

# Prevalence and Monetary Costs of Dementia in Canada

POPULATION HEALTH  
EXPERT PANEL

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**Alzheimer Society**

CANADA

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in collaboration with  
the Public Health Agency of Canada  
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[www.alzheimer.ca](http://www.alzheimer.ca)

# Executive Summary

In May, 2015, the Alzheimer Society of Canada convened a Population Health Expert Panel of epidemiologists, health economists and policy analysts to review available data sources and methodologies to estimate the present and future prevalence and monetary costs of dementia in Canada. The Panel was charged with agreeing on what dementia prevalence and monetary costs in Canada the Society should report to policy makers and the Canadian public.

# Findings & Recommendations

The panel made the following recommendations to the Alzheimer Society of Canada:

## CHALLENGES IN ESTIMATING DEMENTIA PREVALENCE

Estimates of the prevalence of dementia vary because of differences among population-based studies in the definitions of dementia, tests used to measure dementia, the age and other characteristics of sample members, and other factors. The Canadian Study of Health and Aging (CSHA) remains the best single population data source to use as a basis to build estimates. In future, the Alzheimer Society of Canada should propose that prevalence estimates be routinely generated from provincial health administrative data and that when a population-based study such as the Canadian Longitudinal Study on Aging becomes available, it should be used to validate these estimates.

## CURRENT ESTIMATES AND PROJECTIONS OF DEMENTIA PREVALENCE IN CANADA

Using rates drawn from the Canadian Study on Health and Aging, it was estimated that in 2016 there were 564,000 persons in Canada living with dementia. By 2031 it is estimated that the number will increase to 937,000 (see Table 2). More than 65 percent of these will be women.

Analyses by the Mental Health Commission of Canada suggest that when mild cognitive impairment is included, the dementia and mild cognitive

impairment prevalence estimate would be about 50 percent higher than if only dementia is included in the estimate (Figure 4).

## CHALLENGES IN ESTIMATING DEMENTIA MONETARY COSTS

In estimating the monetary costs entailed in caring for persons with dementia, studies should explicitly identify in their analyses what costs are included (such as direct, indirect/informal and intangible costs), who incurs them (such as the health care system, patients and family members) and what monetary values are assigned to personnel and other resources in the community caring for persons with dementia compared with others who do not have dementia. While there is unavoidable uncertainty in estimating and projecting these costs, informal caregiving should be counted among them.

## CURRENT ESTIMATES AND PROJECTIONS OF THE MONETARY COSTS OF DEMENTIA IN CANADA

According to the microsimulation analysis of the National Population Health Study of Neurological Conditions, total health care system costs and out of pocket costs of caring for people with dementia were \$10.4 billion in 2016, and are projected to double by 2031 (Figure 9 and Table 4). Costs for those with dementia are estimated to be five and one-half times greater than for those who are dementia-free. Long-term care and home care are

the largest contributors to direct costs. In addition, the estimated 19.2 million hours of informal unpaid caregiver time in 2011 (conservatively valued at \$1.2 billion) is projected to double by 2031.

Demographic trends suggest that the costs associated with those living with dementia and their caregivers will increase rapidly unless there are significant reductions in the incidence of dementia.

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# Acknowledgements

This report is the result of a meeting of the Population Health Panel of experts who assembled on May 8 and 9, 2015, convened by the Alzheimer Society of Canada and the Public Health Agency of Canada. The Population Health Panel was informed in its deliberations by a background paper (Grignon M, Spencer B, Bronskill S, Mulvale G, Gandhi S, Winkup J, Wang L. On the Prevalence and Cost of Dementia in Canada: A Review of the Evidence. McMaster University, Hamilton and Institute of Clinical Evaluative Sciences, Toronto. 2015) and by papers based on the Canadian Population Health Study of Neurological Conditions (Manuel DG, Garner R, Fines P, Bancej C, Flanagan W, Tu K, Reimer K, Chambers LW, Bernier J. Alzheimer's and other dementias in Canada 2011 to 2031: A POHEM microsimulation modelling study of projected prevalence, health burden, health services and caregiving use. Working document, 2015, and Bancej C, Tu K, Reimer K, Fines P, Zycki A, Green D, Sutherland J, Garner R, Manuel D, Wall R, Bernier J. Current and projected direct and informal care costs among Canadians diagnosed with Alzheimer's Disease and other dementias – A microsimulation study. Working Document, 2015).

The Population Health Panel was assembled to provide the Alzheimer Society of Canada an independent review of dementia prevalence and monetary costs. The Readers of this report also provided candid and critical comments that assisted the Alzheimer Society of Canada in making its published report as sound as possible and to ensure the report meets Society standards for objectivity, evidence, and responsiveness to the study charge.

The review comments remain confidential to protect the integrity of the deliberative process. We thank the Expert Panel and the Readers.

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# Contents

- 2** EXECUTIVE SUMMARY
- 3** FINDINGS & RECOMMENDATIONS
- 6** ACKNOWLEDGEMENTS
- 11** 1.0 RATIONALE FOR THIS REPORT
- 12** 2.0 VARIABILITY IN COGNITIVE AGING
- 13** 3.0 MEASUREMENT OF COGNITIVE IMPAIRMENT AND DEMENTIA
- 15** 4.0 WHAT IS DEMENTIA PREVALENCE?
- 16** 5.0 WHAT ARE THE SOURCES OF INFORMATION ON DEMENTIA IN CANADA?
- 18** 6.0 THE CANADIAN STUDY OF HEALTH AND AGING 1991-2001 (CSHA)
- 19** 7.0 THE CANADIAN LONGITUDINAL STUDY ON AGING (CLSA)
- 20** 8.0 REPORTS ON PRESENT AND FUTURE DEMENTIA PREVALENCE
- 26** 9.0 ISSUES IN ESTIMATING AND PROJECTING DEMENTIA PREVALENCE
- 27** 10.0 RECOMMENDED 2015 ALZHEIMER SOCIETY MESSAGES ABOUT DEMENTIA PREVALENCE
- 28** 11.0 MONETARY COSTS OF DEMENTIA
- 29** 12.0 ISSUES IN ESTIMATING PRESENT AND FUTURE MONETARY COSTS OF DEMENTIA: PERSPECTIVE, SCOPE AND VALUATION
- 30** 13.0 REPORTS ON PRESENT AND FUTURE DEMENTIA MONETARY COSTS
- 34** 14.0 MICROSIMULATION USED IN NATIONAL POPULATION HEALTH STUDY OF NEUROLOGICAL CONDITIONS

<b>40</b>	15.0 RECOMMENDED 2015 ALZHEIMER SOCIETY MESSAGES ABOUT MONETARY COSTS
<b>41</b>	16.0 GENERATING ESTIMATES OF DEMENTIA PREVALENCE AND MONETARY COSTS IN CANADA'S PROVINCES
<b>42</b>	17.0 PRODUCTION OF THIS REPORT ON DEMENTIA PREVALENCE AND MONETARY COSTS
<b>44</b>	18.0 SUMMARY
<b>45</b>	19.0 REFERENCES
<b>51</b>	BOX 1 ESTIMATING MONETARY COSTS: PERSPECTIVE, SCOPE AND EVALUATION
<b>51</b>	1 PERSPECTIVE
<b>53</b>	2 SCOPE
<b>54</b>	3 ATTRIBUTING COSTS TO DEMENTIA
<b>60</b>	APPENDIX A: ON THE PREVALENCE AND COST OF DEMENTIA IN CANADA: A REVIEW OF THE EVIDENCE
<b>61</b>	APPENDIX B: ALZHEIMER'S AND OTHER DEMENTIAS IN CANADA, 2011 TO 2031: A MICROSIMULATION POPULATION HEALTH MODELING (POHEM) STUDY OF PROJECTED PREVALENCE, HEALTH BURDEN, HEALTH SERVICES, AND CAREGIVING USE
<b>62</b>	APPENDIX C: POPULATION HEALTH EXPERT PANEL BIOGRAPHIES



# Tables

21	<b>TABLE 1</b>	REPORTS ON PRESENT AND FUTURE DEMENTIA PREVALENCE BY DATA SOURCE AND INCLUSION OF MILD COGNITIVE IMPAIRMENT
22	<b>TABLE 2</b>	ESTIMATED NUMBER OF CANADIANS AGED 65 YEARS AND OVER WITH DEMENTIA: 2014 AND 2033
31	<b>TABLE 3</b>	FIVE REPORTS ON COSTS OF DEMENTIA BY PERSPECTIVE, SCOPE AND VALUATION
32	<b>TABLE 4</b>	ANNUAL ESTIMATED DIRECT COSTS OF DEMENTIA IN 2011, 2021, AND 2031 IN FIVE REPORTS
52	<b>TABLE 5</b>	HOW PERSPECTIVES INFLUENCE WHICH COSTS ARE COUNTED IN A COST ANALYSIS

# Figures

14	<b>FIGURE 1</b>	CHANGING THRESHOLD FOR 'DEMENTIA' TO INCLUDE 'MILD COGNITIVE IMPAIRMENT' CREATES NEW PATIENTS (OVERDIAGNOSIS) AND OVERTREATMENT
17	<b>FIGURE 2</b>	POSSIBLE HEALTH ADMINISTRATION DATA SOURCES OF DEMENTIA PREVALENCE
24	<b>FIGURE 3</b>	AGE PYRAMIDS AND NUMBER OF THE CANADIAN POPULATION: 2009, 2036, 2061
25	<b>FIGURE 4</b>	DEMENTIA PREVALENCE IN CANADA, 2011, 2021, AND 2031 - ESTIMATES FROM FOUR SOURCES

<b>33</b>	<b>FIGURE 5</b>	<b>COSTS OF CAREGIVING – TOTAL OUT-OF-POCKET COSTS TO CAREGIVERS OF PEOPLE WITH DEMENTIA ARE PROJECTED TO RISE TO BILLIONS ANNUALLY IN 2031, CANADA</b>
<b>36</b>	<b>FIGURE 6</b>	<b>CANADIAN NATIONAL POPULATION HEALTH STUDY OF NEUROLOGICAL CONDITIONS: SIMULATION MODEL</b>
<b>37</b>	<b>FIGURE 7</b>	<b>PROJECTED DIRECT HEALTH CARE COSTS OF DEMENTIA BY SECTOR AND AGE CATEGORY, CANADA, 2011</b>
<b>38</b>	<b>FIGURE 8</b>	<b>PROJECTED TOTAL DIRECT HEALTHCARE SYSTEM COSTS ATTRIBUTED TO DEMENTIA, BY AGE CATEGORY (ONSET &lt; 65 YEARS VS. ONSET &gt;= 65 YEARS) AND YEAR, CONSTANT \$CDN 2010</b>
<b>39</b>	<b>FIGURE 9</b>	<b>PROJECTED TOTAL HEALTH SYSTEM COSTS AND OUT OF POCKET CAREGIVING COSTS (\$MILLION) TO PERSONS WITH DEMENTIA, CONSTANT \$CDN 2010, 2011 TO 2013</b>
<b>43</b>	<b>FIGURE 10</b>	<b>PROCESSES USED IN PREPARING THE REPORT OF THE EXPERT PANEL OF THE ALZHEIMER SOCIETY OF CANADA</b>
<b>56</b>	<b>FIGURE 11</b>	<b>COST VALUATION: INFORMAL COSTS OF CAREGIVING AND MULTI-TASKING</b>
<b>57</b>	<b>FIGURE 12</b>	<b>PERCENTAGES OF RESIDENTS WITH DEMENTIA IN COMMUNITY VERSUS INSTITUTIONS, CANADA (PROVINCES AND TERRITORIES), 2011-2031</b>
<b>58</b>	<b>FIGURE 13</b>	<b>COST OF DEMENTIA BY STAGE OF DEMENTIA, CANADA</b>
<b>59</b>	<b>FIGURE 14</b>	<b>COST VALUATION: COMMUNITY-WIDE HOUSING OPTIONS FOR OLDER ADULTS REQUIRING CONTINUING CARE BY LEVEL OF DEPENDENCY AND PERCENTAGE WITH DEMENTIA BY LOCATION</b>

# 1.0 Rationale for this Report

Uses of estimates of present and future dementia prevalence and monetary costs include:

- Improving the public's awareness of the public health importance of dementia and the high financial costs and care experienced by those living with dementia and by their caregivers.
- Documenting costs of care, loss of income, and other financial challenges for patients and their families.
- Providing benchmarks against which future progress can be assessed using estimates that are user friendly but robust so all sectors can use them with confidence.
- Informing service planning and policy development at all levels, such as a national dementia strategy for Canada, governmental and non-governmental organizations' work plans, budgets and projections.

## 2.0 Variability in Cognitive Aging

There is a wide spectrum of types of cognitive impairment and dementia, and these conditions have varied causes and consequences. In 2015, 80 years is the average age of onset of dementia (Grignon et al 2015). According to the recent review entitled “Cognitive Aging” (Institute of Medicine 2015), cognitive aging differs in the populations of 60 year olds, 70 year olds, 80 year olds and those 90 and over. And the increased likelihood of co-existing cardiovascular disease, diabetes and dementia with advancing aging exacerbate cognitive declines (Bunn et al 2014). Further, studies of populations show that older people perform less well, and cognitive health differs according to educational background, health status, literacy, culture, ethnicity, skills, abilities, and life experiences. Also, a person’s cognitive trajectory over time is dynamic with ups and downs because of environmental stressors, medications or illnesses. Dementia is one of the main causes of disability later in life, ahead of cancer, cardiovascular disease and stroke. On a positive note, the Institute of Medicine review points to the concept of neural plasticity and findings that older adults learn new skills and improve cognitive performance, and that they have a wealth of knowledge, skills and experience younger people may not have.

# 3.0 Measurement of Cognitive Impairment and Dementia

Dementia refers to progressive impairments in memory and other cognitive functions. A diagnosis of dementia is based on a pattern of signs & symptoms such as the ten warning signs of dementia: 1. Memory loss that affects day-to-day abilities, 2. Difficulty performing familiar tasks, 3. Problems with language such as forgetting or using wrong words, 4. Disorientation in time and space, 5. Impaired judgement, 6. Frequent problems with complicated tasks, 7. Misplacing things, 8. Sudden changes in mood and behavior, 9. Changes in personality, and 10. Loss of interest in doing things (Alzheimer Society of Canada 2015). Dementia lies at the severe end of a spectrum of cognitive disorders and the level of disability and need for care rises across the spectrum. It is difficult to set a precise threshold between cognitive impairment and dementia.

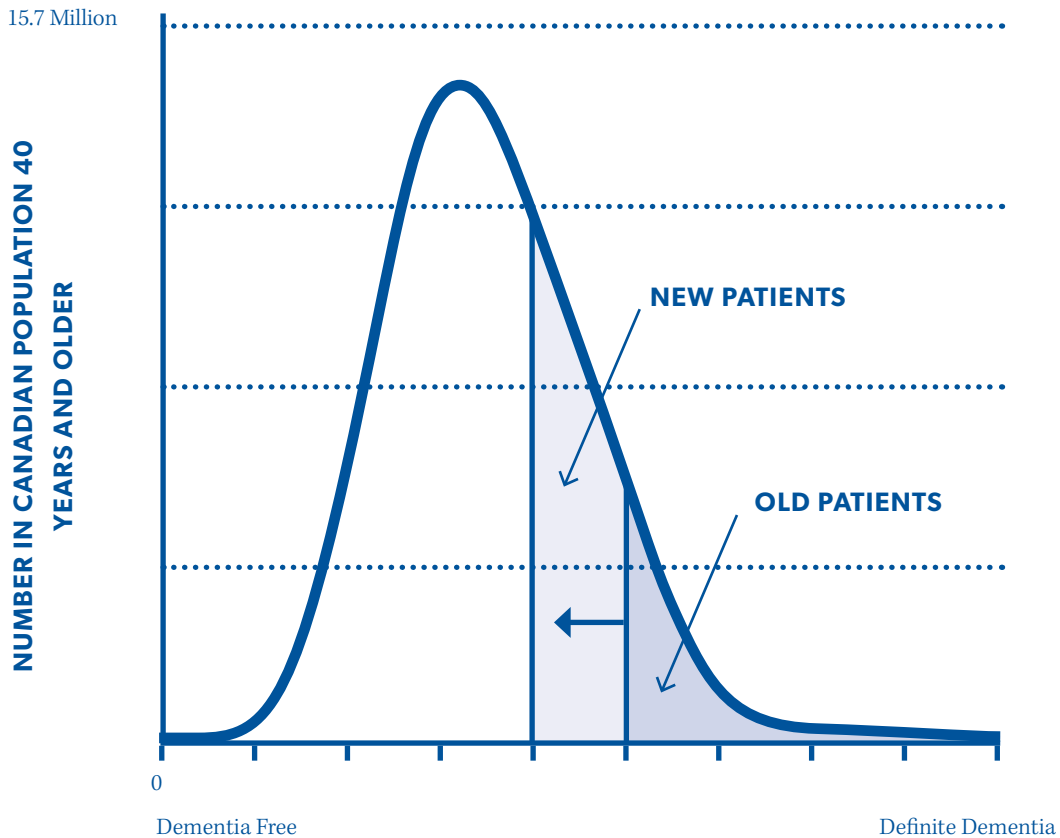
The US Preventive Services Task Force (Lin et al 2013) identified the following cognitive impairment screening tests as accurate as their psychometric properties are reported to be greater than 80 to 90 percent sensitivity and specificity:

- Mini-Mental State Exam
- Clock drawing test
- Mini-cog test
- Memory impairment screen
- Abbreviated mental test
- Short Portable Mental Status Questionnaire
- Free and cued selective reminding test
- 7-minute screen
- Telephone Interview for Cognitive Status
- Information Questionnaire on Cognitive Decline in the Elderly

International population surveys of prevalence of mild cognitive impairment estimates vary from 5% to 37% (Sachdev et al 2015). Sometimes “mild cognitive impairment”, typically identified using one or more of these screening tests, is counted as “dementia” in population prevalence estimates. However, only about 60% of people with mild cognitive impairment progress to dementia and experience disability (Savva et al, 2009). Changing the threshold for ‘dementia’ to include mild cognitive impairment may create new patients (overdiagnosis) and, in clinical settings, result in overtreatment (Figure 1) (Welch et al 2011, Lin et al 2013, Institute of Medicine 2015). The Gerontology Society of America Workgroup on Cognitive Impairment Detection and Earlier Diagnosis (2015) concluded there is lack of evidence that specific medical conditions or functional limitations are inevitably linked to development of any type of dementia. And, this Workgroup went further, choosing not to endorse any specific risk factors for dementia that would automatically trigger the need for cognitive assessment (The Gerontology Society of America Workgroup on Cognitive Impairment Detection and Earlier Diagnosis 2015).

**FIGURE 1**

CHANGING THRESHOLD FOR 'DEMENTIA' TO INCLUDE 'MILD COGNITIVE IMPAIRMENT' MAY CREATE NEW PATIENTS (OVERDIAGNOSIS) AND OVERTREATMENT (Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)



Source:  
Adapted from: Welch et al (2011).

## 4.0 What is Dementia Prevalence?

Prevalence refers to the number or percentage of people who have dementia. Dementia incidence is the number or frequency of people who are newly diagnosed with dementia in a given period. Incident cases are new cases while prevalence counts the total number of existing cases, old and new, for the time period studied. Prevalence will exceed incidence, reflecting the duration of survival of people with dementia, which has been increasing. In a steady state, prevalence is equal to incidence multiplied by length of survival. Because the prevalence of dementia rises with age it is desirable to calculate age-standardized prevalence when comparing between populations if their age-structures differ. Prevalence, incidence and survival figures serve different purposes. Prevalence summarizes the overall magnitude of the disorder in the population. Incidence is used to indicate the possible impact of preventive measures. Survival is used as a marker of success in treatment.

## 5.0 What are the Sources of Information on Dementia in Canada?

Dementia prevalence and monetary costs in the population can be estimated using two sources of information: community health surveys and health administrative databases (or combinations of these) (Figure 2).

Community surveys involve trained interviewers who contact people in the community and ask them and/or their caregivers about their health, and administer simple cognitive tests. Some respondents may then undergo further medical testing at a study clinic; the additional information collected can supplement the cognitive testing to allow neuropsychologist interpretation of test results. Such studies provide estimates for dementia prevalence in a population. However, results vary: self-reported survey data relevant to dementia are not likely to be accurate and Canadians living in the community may not be reliable sources of information on neurological conditions, even when proxy responses are included (Loney et al 1998 and Erkinjunnti et al 1997). Reflecting this, the prevalence estimate for dementia derived from the Canadian Community Health Survey (2010–2011) was much lower than an estimate obtained from a meta-analysis (Grignon et al 2015).

Health administrative data can be a second source. When people access the health care system, administrative data are created, for example, recording each encounter with a physician and each hospital visit, Clinical point of care assessment data, for example using the InterRAI data collection system in long term care facilities and homecare programs, are collected for administrative purposes but can

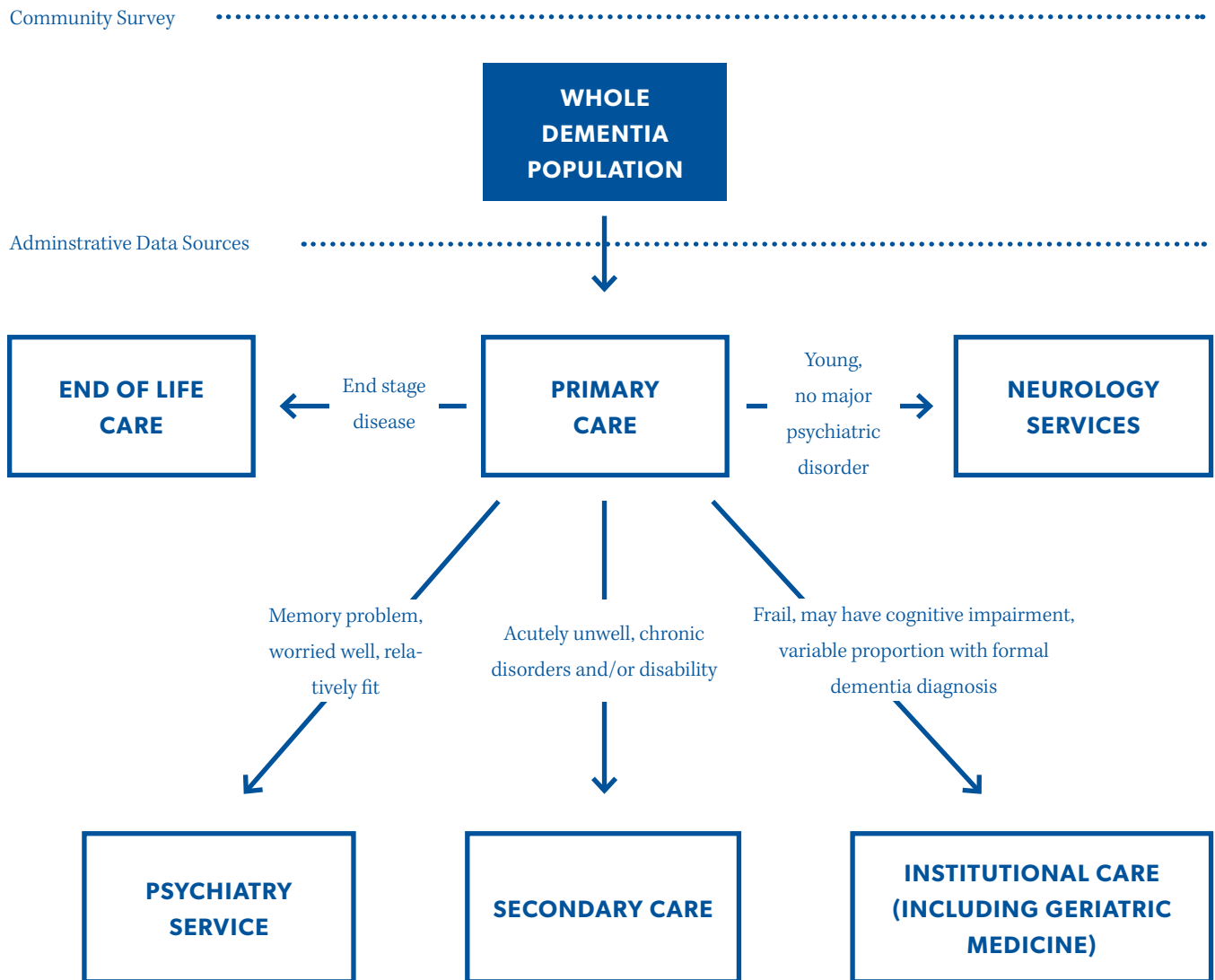
also be used in research studies (Danila et al 2014). Computer files within hospitals and for physicians who have electronic medical records are used to store basic information such as reason for the visit, diagnosis and medications prescribed. These data are used to reimburse providers but also can be used in estimating prevalence, incidence and monetary costs of dementia. Several service delivery locations generate administrative data (Figure 2) but many such databases do not cover all these locations and the records are often incomplete. For example, interRAI data are not collected in every Canadian province, limiting comparisons across long term care facilities or home care programs. In the absence of a unitary system such greater established validity of data generated using interRAI, information on dementia prevalence can be assembled from various sources using clinical algorithms. For example, persons with a diagnosis of dementia admitted to a hospital, persons for whom dementia was the reason for three visits to a family physician, and/or persons who were prescribed a drug used in the treatment of dementia could each be counted by the algorithm as a “dementia case”.



**FIGURE 2**

POSSIBLE COMMUNITY SURVEY AND HEALTH ADMINISTRATIVE DATA SOURCES FOR ESTIMATING DEMENTIA PREVALENCE

(Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)



\*Note = the dash lines indicate that only a portion of those in one clinical service are referred to each further group of clinical service. If the data is not linked across clinical services, then care received in other clinical services may not be available in the health administrative data for a province.

Source:

Adapted from Brayne C. Personal Communication. May 2015.

## 6.0 The Canadian Study of Health and Aging 1991-2001 (CSHA)

The last Canada-wide population health survey to estimate dementia prevalence and incidence was the Canadian Study of Health and Aging (Canadian Study of Health and Aging Working Group, 1994). This commenced in 1991 and study participants were followed up in 1996 and 2001. In 1991, interviews and questionnaires were conducted with 9,008 people 65 years and over living in the community and 1,255 living in long term care facilities. Clinical, neurological and neuropsychological examinations were carried out with 2,914 people who had been interviewed and had low cognitive scores, and with a random sample of people with 'normal' scores. A clinical consensus conference involving a physician, a nurse and a neuropsychologist decided on whether people should be classified in terms of probable dementia, definite dementia and type of dementia. This is consistent with the present way in which dementia is diagnosed in a clinical setting, using multiple data sources and with input from more than one health care professional. Autopsies are seldom done even though this is also a superior way of diagnosing dementia. Prevalence estimates derived from health administrative data and data using InterRAI are not based on standardized clinical assessments as in the CSHA or on autopsies.

## 7.0 The Canadian Longitudinal Study on Aging (CLSA)

The Canadian Longitudinal Study on Aging is a signature initiative of the Canadian Institutes of Health Research (CIHR) (Raina et al 2009). The study involves more than 160 researchers in 26 centres. The CLSA has created a research platform that follows a baseline cohort of 51,352 Canadian men and women aged 45 to 85. Among the many data to be generated will be new Canadian estimates of dementia incidence, length of time with disease to death, caregiving and health care use. Incidence, but not prevalence, can be generated from the CLSA, since entry into the study excluded anyone who was thought to be cognitively impaired (using interviewer judgement) so only people who are newly diagnosed with dementia in follow-up years will be identified.

Similarly to the CSHA, 30,000 of the CLSA participants will undergo three-hour clinical, neurological and neuropsychological examinations every three years. A dementia algorithm was developed to use these data to identify dementia ‘cases’.

Dementia prevalence estimates derived from administrative data are known to produce lower estimates than community surveys. This is because not all cases of dementia (especially early or mild cases that are not diagnosed as dementia) are recorded in administrative data sources and because such data only capture those who access or use health care services. The CLSA data can be linked with provincial administrative data bases and so could provide data by which to validate the number of incident cases that may be missed using health administrative data bases. Average time in

each stage of dementia with its associated level of disability can inform the cost estimates, especially dementia cost projections. The CLSA could provide these types of data in future years. However, the CLSA’s present dementia ascertainment algorithm does not classify dementia into stages and the recruited population is biased towards the healthy.

The CLSA could provide new information on the impact of demographic changes, the preventive effects of a possibly healthier generation of older adults on changing care costs, and the possibility (and costs) of new therapies.

# 8.0 Reports on Present and Future Dementia Prevalence

Table 1 shows recent Canadian reports on present and future dementia prevalence and monetary costs by data source and inclusion of mild cognitive impairment. The point estimates differ depending on the source of the data (population surveys versus administrative data bases) and on whether mild cognitive impairment is included in the estimates. The highest estimates are from the health administration data analyses from Manitoba that were included in the Mental Health Commission of Canada Report (2011) (Martens et al. 2004). This is likely because, unlike the other three reports, it included mild cognitive impairment. The CSHA (1994) as well as estimates from the EURODEM synthesis of studies (Jorm et al 1998) were the main source of data for the Rising Tide Report (Alzheimer Society of Canada 2010). Health administrative data from British Columbia and Ontario and other population health data were used by the National Population Health Study of Neurological Conditions (Public Health Agency of Canada 2014b).

The estimates from the Rising Tide Report and from the Canadian Study of Health and Aging identify approximately 140,000 more cases of dementia than the National Population Health Study of Neurological Conditions. The latter study may provide a lower estimate because it was largely based on health administrative data that do not include individuals who do not access the health care system, whereas the CSHA did identify such people. As shown in Figure 4, the age groups studied varied from all ages to only those 65 years and older. The variation in estimates across studies

is also due to the use of different denominators, notably whether or not institutional populations are included.

Figure 3 illustrates the demographic changes, including the size and aging of the population with age pyramids for the years 2009, 2036 and 2061, according to Statistics Canada. Driven by these demographic changes, prevalence projections from the four reports agree that the numbers of Canadians aged 65 and older with dementia will double over the next 20 years (Figure 4). Table 2 provides estimates of the dementia prevalence for 2014 and 2033. These estimates are based on the Canadian Study on Health and Aging 1991 prevalence figures, extrapolated using Statistics Canada age and sex population estimates for 2014 and projections for 2033. Note that these estimates are for different years than those in Figure 4. These projections assume no changes in mortality, incidence and other factors. As monetary costs projections were available to 2031 in the National Population Health Study of Neurological and to have the projection years coincide, prevalence projections to 2031 are reported in the recommendations in this report.

**TABLE 1**

REPORTS ON PRESENT AND FUTURE DEMENTIA PREVALENCE BY DATA SOURCE AND INCLUSION OF MILD COGNITIVE IMPAIRMENT

(Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)

	Admin Data	Survey and Clinical Exam	European Data*	Mild Cognitive Impairment
Mental Health Commission of Canada, 2012	Yes	No	No	Yes
Rising Tide, 2010 (Alzheimer Society of Canada)	No	Yes	Yes	No
Canadian Study of Health and Aging, 1994	No	Yes	No	Yes***
National Population Health Study of Neurological Conditions, 2014	Yes	Yes**	No	No

\* = Population surveys

\*\* = Surveys but not clinical exams

\*\*\* = Figure 4 in this 2015 Report excludes cognitive impairment no dementia (CIND) although CIND was measured in the study

Sources:

Alzheimer Society of Canada (2010), Mental Health Commission of Canada (2010), Canadian Study of Health and Aging Working Group (1994), Public Health Agency of Canada (2014b).

**TABLE 2**ESTIMATED NUMBER OF CANADIANS AGED 65 YEARS AND OVER WITH  
DEMENTIA: 2014 AND 2033

(Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)

## a. Number of Canadians age 65 years and over with dementia, by age and sex, 2014

Age group (years)	Females			Males			
	Prevalence (%)	Estimated Cdn. Pop. (2014)	Estimated number	Prevalence (%)	Estimated Cdn. Pop. (2014)	Estimated number	
65-74	2.8	1,629,200	45,618	1.9	1,516,300	28,810	
75-84	11.6	950,900	110,304	10.4	757,900	78,822	
85+	37.1	483,700	179,453	28.7	247,200	70,946	
Total			335,375			178,578	513,953
%			65			35	100

## b. Number of Canadians age 65 years and over with dementia, by age and sex, 2033

Age group (years)	Females			Males			
	Prevalence (%)	Estimated Cdn. Pop. (2033)	Estimated number	Prevalence (%)	Estimated Cdn. Pop. (2033)	Estimated number	
65-74	2.8	2,483,900	69,549	1.9	2,389,000	45,391	
75-84	11.6	1,875,200	217,523	10.4	1,660,800	172,723	
85+	37.1	853,600	316,686	28.7	575,200	165,082	
Total			603,758			383,196	986,954
%			61			39	100

## Sources:

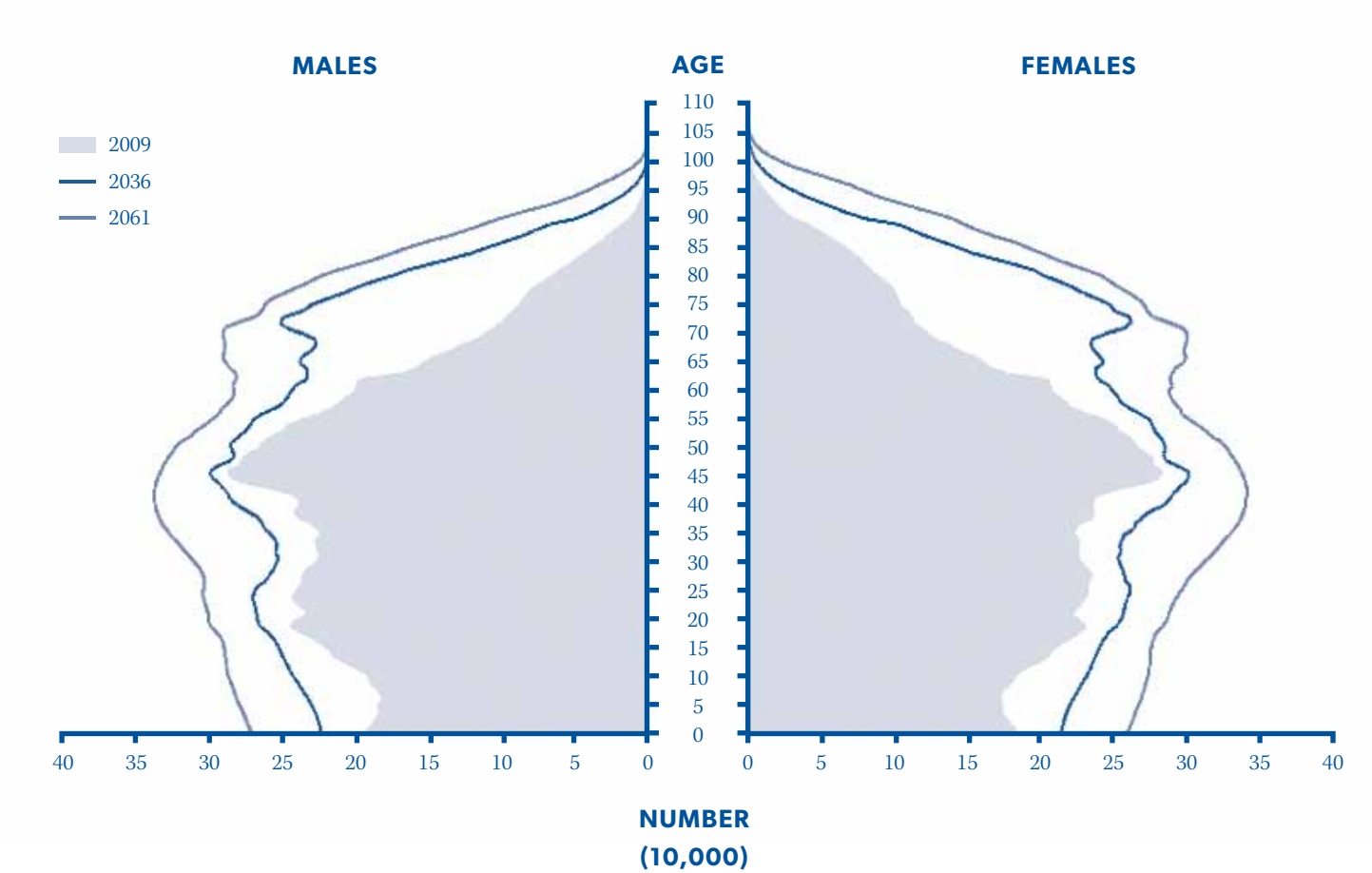
Population estimates (year 2014): <http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/demo10a-eng.htm>Dementia prevalence estimates: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1486712/>Population estimates (year 2033, medium growth): <http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/demo23f-eng.htm>

c. Estimated Prevalence of Dementia by Year: 2014 to 2033

Year	Prevalence	Year	Prevalence
2014	514,000	2024	763,000
2015	539,000	2025	788,000
2016	564,000	2026	813,000
2017	587,000	2027	838,000
2018	614,000	2028	863,000
2019	638,000	2029	887,000
2020	663,000	2030	912,000
2021	688,000	2031	937,000
2022	713,000	2032	962,000
2023	738,000	2033	987,000

### FIGURE 3

AGE PYRAMIDS AND NUMBER OF THE CANADIAN POPULATION, 2009, 2036, 2061  
(Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)



Source:

Statistics Canada, Demography Division, 2012-12-20, <http://www.statcan.gc.ca/pub/91-520-x/2010001/ct047-eng.htm>



**FIGURE 4**

DEMENTIA PREVALENCE IN CANADA, 2011, 2021, AND 2031 - ESTIMATES FROM FOUR SOURCES  
 (Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)



Sources:

MHCC = Mental Health Commission of Canada (Mental Health Commission of Canada, 2011) (People 55 years and over)

Rising Tide = Rising Tide: Impact on Dementia on Canadian Society (Alzheimer Society of Canada, 2010) (All ages)

CSHA = Canadian Study of Health and Aging (Canadian Study of Health and Aging Working Group, 1994) (People 65 years and over)

NPHSNC = National Population Health Study of Neurological Conditions (Public Health Agency of Canada, 2014b) (People 40 years and over)

# 9.0 Issues in Estimating and Projecting Dementia Prevalence

Given the limitations of administrative data to arrive at population estimates of the prevalence of dementia, the CSHA data remain the best available source for this purpose. However, CSHA is limited by being somewhat dated and restricted to assessing only individuals aged 65 years and older. Further, since 1991, when CSHA was first conducted, there have been changes in diagnostic approaches, changes which have possibly led to people being diagnosed at an earlier stage of their condition. This is counterbalanced by evidence from economically developed countries showing that incidences of dementia may be declining because of higher levels of education, greater health awareness and in some cases better control of vascular risk factors (Wu et al. 2015, Ng et al. 2015, Satizabal et al. 2016, Jones et al. 2016, Mayeda et al. 2016).

If the estimate of the total impaired (dementia and mild cognitive impairment) is to be presented perhaps some other term, for example cognitive impairment or impaired cognition, rather than dementia, would be more accurate.

Differences among studies in the definitions of dementia, in the tests used to measure cognition, in the age and other characteristics of sample members, and other factors produce variation in the estimates of the prevalence of dementia. Because of these challenges in establishing population data on dementia, the Alzheimer Society of Canada should in future promote prevalence estimates that are generated from provincial

administrative data and that emerging data from the Canadian Longitudinal Study on Aging be used to validate these estimates.

# 10.0 Recommended 2015 Alzheimer Society Messages about Dementia Prevalence

## CHALLENGES IN ESTIMATING DEMENTIA PREVALENCE

Estimates of the prevalence of dementia vary because of differences among population-based studies in the definitions of dementia, tests used to measure dementia, the age and other characteristics of sample members, and other factors. The Canadian Study of Health and Aging (CSHA) remains the best single population data source to use as a basis to build estimates. In future, the Alzheimer Society of Canada should propose that prevalence estimates be routinely generated from provincial health administrative data and that when a population-based study such as the Canadian Longitudinal Study on Aging becomes available, it should be used to validate these estimates.

## CURRENT ESTIMATES AND PROJECTIONS OF DEMENTIA PREVALENCE IN CANADA

Using rates drawn from the Canadian Study on Health and Aging, it was estimated that in 2016 there were 564,000 persons in Canada living with dementia. By 2031 it is estimated that the number will increase to 937,000 (see Table 2). More than 65 percent of these will be women.

Analyses by the Mental Health Commission of Canada suggest that when mild cognitive impairment is included, the dementia and mild cognitive impairment prevalence estimate would be about 50 percent higher than if only dementia is included in the estimate (Figure 4).

# 11.0 Monetary Costs of Dementia

Costs of care can be calculated in several different ways, and the purpose(s) for which the costs are being estimated is a key determinant of the methodological choices made for estimating costs.

Potential purposes include:

- Understanding how much dementia costs society.
- Understanding the scale of the resources required to care for people with dementia. This is important given that good care for people with dementia, whether it is to deal with the dementia itself or with co-morbidities, ideally requires specially trained care providers, such as specialist dementia wards in acute hospitals, specialist nursing homes and day care.
- Showing who is responsible for the expenditures and/or costs, public or private. Compared to other health conditions, a very large proportion of the costs of dementia care falls on the families of people with dementia and they provide “unpaid” care. The public system only covers a fraction of the total costs of dementia. Some studies report that two-thirds of the costs are indirect and fall on families, and include cash and in kind expenditures (see for example, Prince et al 2014b).
- Assessing the impact that new drugs to treat or cure Alzheimer’s or other types of dementia could have on increasing or reducing the costs of dementia, or the costs of programs (Cheng 2013).

# 12.0 Issues in Estimating Present and Future Monetary Costs of Dementia: Perspective, Scope and Valuation

Three types of issues need to be considered in cost analyses:

- The *perspective*: who bears the costs? Is the analysis concerned with the cost to health insurance only (public, private or both) or to society as a whole, including the people with dementia, their caregivers, and employers?
- The *scope*: which direct, indirect/informal, and intangible costs are to be included?
- The *method*: how are the costs measured? This issue is most difficult for indirect costs, such as informal caregiving, do not come with observable price tags, but even in the case of direct costs it is not enough simply to count costs that accrue to persons with dementia; instead the analyst must find a way to attribute a cost that is specific to dementia – a cost that would not otherwise exist.

These issues are described further in Box 1. In addition, these issues are covered in more detail in the background report on prevalence and monetary costs of dementia prepared for the Alzheimer Society of Canada (Grignon et al. 2015) and the working paper (Manuel et al 2016) provided to the Expert Panel before their meeting in May 2015 (see Appendices A and B).

# 13.0 Reports on Present and Future Dementia Monetary Costs

Five reports have provided estimates of present and future Canada-wide monetary costs of dementia (Table 3): the Mental Health Commission of Canada (2010), Rising Tide (Alzheimer Society of Canada 2010), the National Population Health Study of Neurological Conditions (Public Health Agency of Canada 2014b), Economic Burden of Illness in Canada (Public Health Agency of Canada 2014a) and the Canadian Study of Health and Aging (1994). All five reports take a societal perspective in their cost analyses. Only the Population Health Study of Neurological Conditions (Public Health Agency of Canada 2014b) includes direct, indirect and intangible costs (Table 3).

The five reports took different approaches to how they attributed costs to dementia. In contrast to the other four reports, the Population Health Study of Neurological Conditions (Public Health Agency of Canada 2014b) was the only one that included observable and non-observable costs attributed to dementia (Table 3). The non-observable dementia costs were based on self-reports of functional health, basing the value of each health state on the Health Utilities Index (HUI)-3 (Horsman et al 2003). The observable dementia costs were based on expenditures of government programs (inpatient services, community services, pharmaceutical, and other services) and self-reports about presence of caregiver, hours of informal care and out-of-pocket costs. In addition, the costs of dementia compared physician-diagnosed dementia with a counterfactual cohort without a physician diagnosis of dementia using linked administrative data bases in British Columbia and Ontario to estimate costs for Canada.

The five reports varied considerably in their estimates of present and future costs of dementia because of the different methods used, the different definitions of dementia and inclusions of different types of costs and different data sources (Table 4). Three of the reports, the Mental Health Commission of Canada (2012), Rising Tide (Alzheimer Society of Canada 2010, 2012), and National Population Health Study of Neurological Conditions (Public Health Agency of Canada 2014b), included microsimulations that produced projections of future monetary costs. These projections also varied considerably. As shown in the National Population Health Study of Neurological Conditions (Figure 5), informal caregiving contributes a large amount of cost of persons with dementia, so informal caregiving should be counted among present and projected costs of dementia. Demographic trends suggest that the costs associated with those living with dementia and their caregivers will increase rapidly unless there are significant reductions in incidence.

**TABLE 3**

FIVE REPORTS ON COSTS OF DEMENTIA BY PERSPECTIVE, SCOPE AND VALUATION  
(Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)

Report	Perspective	Scope	Attributing Costs to Dementia
Mental Health Commission of Canada (2011)	Societal	Direct	Observable dementia costs: expenditures of government programs (inpatient services, physician services, community and social services, pharmaceuticals, other services and income support)
Rising Tide (2010)	Societal	Direct	Same as Mental Health Commission of Canada
National Population Health Study of Neurological Conditions (2014)	Societal	Direct, indirect and intangible costs	Non observable dementia costs: self-reports of functional health with perceived value of each health state (Health Utilities Index (HUI)-3) Observable dementia costs: expenditures of government programs (inpatient services, community services, pharmaceutical, and other services) and self-reports about presence of caregiver, hours of informal care, out-of-pocket costs
Economic Burden of Illness in Canada (2014)	Societal	Direct costs and indirect	Observable dementia costs: expenditures of government programs (health sector costs), labour market missed work days
Canadian Study on Health and Aging (1994)	Societal	Direct and indirect costs	Observable dementia costs: market value of services used to diagnose, treat, care for, rehabilitate persons with dementia including cost of drugs and costs of unpaid services provided by informal caregivers (family and friends)

Sources:

Mental Health Commission of Canada. Making the Case for Investing in Mental Health in Canada. Calgary. Mental Health Commission of Canada. 2011.

Alzheimer Society of Canada. Rising Tide: The Impact of Dementia on Canadian Society. Alzheimer Society of Canada. Toronto. 2010.

Public Health Agency of Canada. Mapping Connections: An Understanding of Neurological Conditions in Canada – The National Population Health Study of Neurological Conditions. Ottawa. Public Health Agency of Canada. September 2014b. <http://www.phac-aspc.gc.ca/publicat/cd-mc/mc-ec/index-eng.php>. Accessed 2015.

Public Health Agency of Canada. Economic Burden of Illness in Canada, 2005-2008. Ottawa. Public Health Agency of Canada. March 2014a. <http://www.phac-aspc.gc.ca/publicat/ebic-femc/2005-2008/index-eng.php>. Accessed 2015.

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**TABLE 4**

ANNUAL ESTIMATED DIRECT COSTS OF DEMENTIA IN 2011, 2021, 2031 IN FIVE REPORTS  
(Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)

Report	In \$ Millions		
	2011	2021	2031
Mental Health Commission, 2011	19,741	42,231	92,863
Rising Tide	10,794*	25,029	55,351
National Population Health Study of Neurological Conditions**	8,300	N/A	16,600
Economic Burden of Illness in Canada, 2014	910	N/A	N/A
Canadian Study of Health and Aging, 1994	4 (1991)	N/A	N/A

\*Direct costs only. When indirect costs are added the estimate is \$33 billion (Alzheimer Society of Canada 2012).

\*\*Monetary Estimated Prevalence and Monetary Cost of Dementia by Year: 2011 to 2031

Year	\$ Millions	Year	\$ Millions	Year	\$ Millions
2011	8,300	2018	11,205	2025	14,110
2012	8,715	2019	11,620	2026	14,525
2013	9,130	2020	12,035	2027	14,940
2014	9,545	2021	12,450	2028	15,355
2015	9,960	2022	12,865	2029	15,770
2016	10,375	2023	13,280	2030	16,185
2017	10,790	2024	13,695	2031	16,600

Sources:

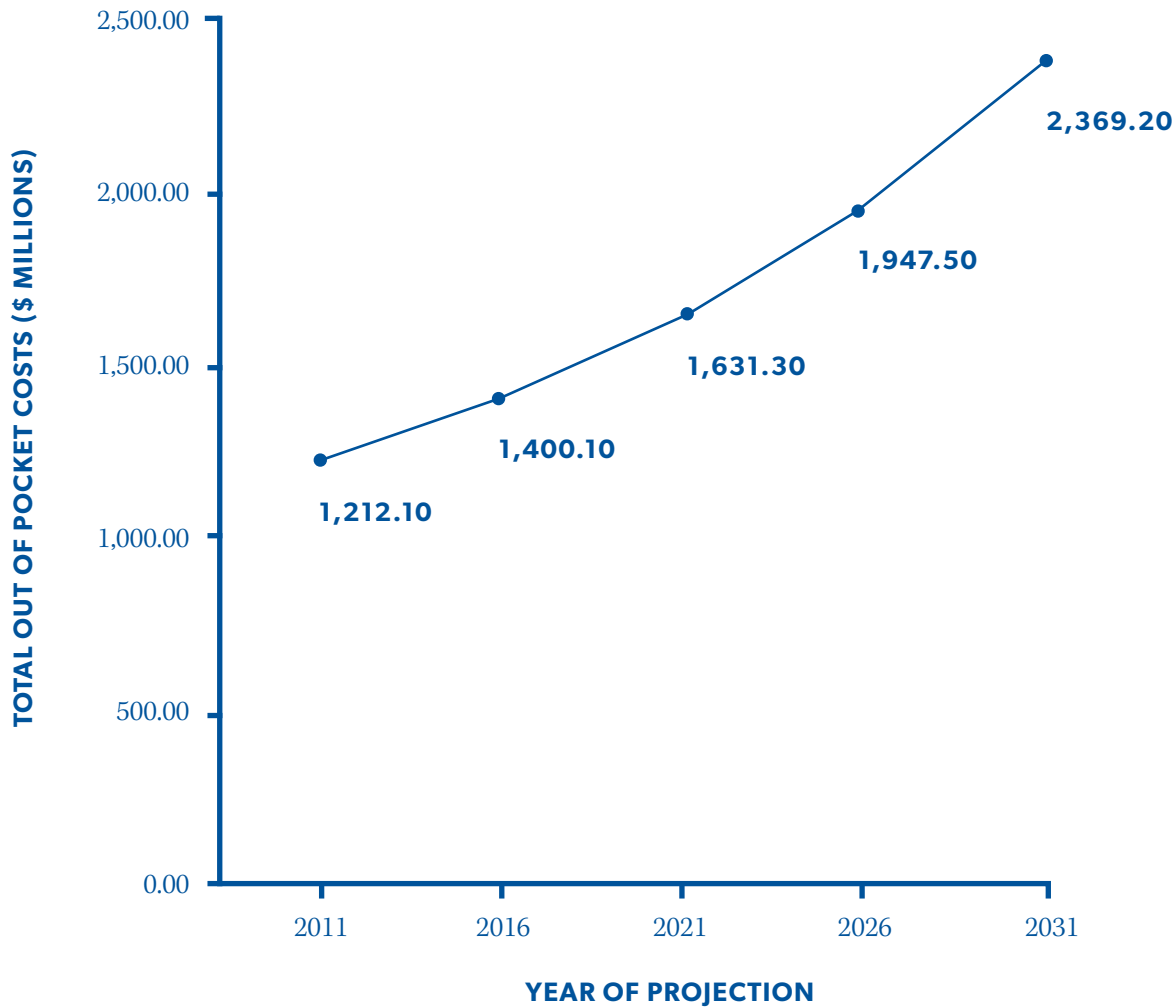
See Alzheimer Society of Canada (2012), Ostbye, et al (1994), Public Health Agency of Canada (2014b), Public Health Agency of Canada (2014c), Mental Health Commission 2011.



**FIGURE 5**

COSTS OF CAREGIVING – TOTAL OUT OF POCKET COSTS TO CAREGIVERS OF PEOPLE WITH ALZHEIMER’S DISEASE AND OTHER DEMENTIAS ARE PROJECTED TO RISE TO BILLIONS ANNUALLY IN 2031, CANADA

(Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)



Source:

National Population Health Study of Neurological Conditions; Bancej C, Tu K, Reimer K, Fines P, Zycki A, Green D, Sutherland J, Garner R, Manuel D, Wall R, Bernier J. Current and projected direct and informal care costs among Canadians diagnosed with Alzheimer’s Disease and other dementias – A microsimulation study. Ottawa. Public Health Agency of Canada. Working Document. 2015.

# 14.0 Microsimulation used in National Population Health Study of Neurological Conditions

In 2014, the National Population Health Study of Neurological Conditions (Public Health Agency of Canada 2014c) was reported but working papers were prepared in 2015 regarding the microsimulation analyses (Manuel et al 2016, Appendix B). Using a population perspective, data sources for the microsimulation (POHEM neurological model) included:

- *Historic and projected births, deaths, and migration* based on data from Statistics Canada,
- *2006-2010 dementia incidence and mortality rates* based on British Columbia health administrative data,
- *Health status* (Health Utilities Index Mark 3 (Horsman et al 2003)). For people without dementia the data source was the National Population Health Survey. For people with dementia, including their Health Utilities Index states of severity data, the source was the Survey on Living with Neurologic Conditions in Canada (Statistics Canada 2011),
- *Caregiving including costs of caregiving* were based on data from the 2012 General Social Survey (Statistics Canada 2012).
- *Health care use and costs for physician services; prescription pharmaceuticals; hospitalizations; rehabilitation; home care services; long-term care; and assistive devices*, based on Health administrative data from Ontario and British Columbia.

The Population Health Expert Panel chose to use this report as the basis for its recommendations about the monetary costs of dementia in

Canada. This decision was based on the quality of the methods and data used in the report. These methods include:

- The algorithm used to identify dementia was three physician visits with 30 days or more between visits in a two-year period, or one hospitalization, or one prescription for a dementia medication; this applied to people over 65 years of age. This validated algorithm did not include mild cognitive impairment.
- Persons with early onset dementia (below age 65) were included in the overall study.
- The main cost drivers of dementia were informal costs due to home-based care and nursing home expenditures, rather than inpatient and outpatient medical services. Informal care referred to care provided by family members, friends and neighbors. Caregiver replacement costs were estimated conservatively by assigning the lowest hourly minimum wage in Canada.
- Lifetime costs of living for each individual with dementia were estimated. For individuals who were diagnosed with dementia for more than one year, costs were assigned specific to their age and sex for both community dwellers and those living in care facilities. Because stage of information was not available in the health administrative data, it was estimated in the microsimulation model.
- Estimated and projected differential costs attributed to dementia were estimated as the difference between costs dementia patients incurred and costs incurred in the absence of a

dementia diagnosis.

- Per person costs of dementia were reported. For example, among persons with prevalent dementia, long-term care costs were the greatest per person with dementia costs at \$14,000 per person per year.

The study is outlined in Figure 6. The study's projected direct health care system but not including out of pocket caregiving (Figure 5) costs for dementia by sector and age category in 2011 are shown in Figure 7. The substantial increases in projected total direct health care system costs attributed to dementia to 2031, by age category (onset less than 65 years versus onset greater than or equal to 65 years) and year in constant \$CDN for 2010 are shown in Figure 8. The total health care system costs including out of pocket caregiving costs of people with dementia in the simulation of the National Population Health Study of Neurological Conditions was estimated to be \$8.3 billion in 2011 and \$16.6 billion in 2031 (Figure 9).

The Population Health Microsimulation Model developed for projecting the future impact of dementia in Canada (POHEM-Neurological: National Population Health Study of Neurological Conditions) has the following features:

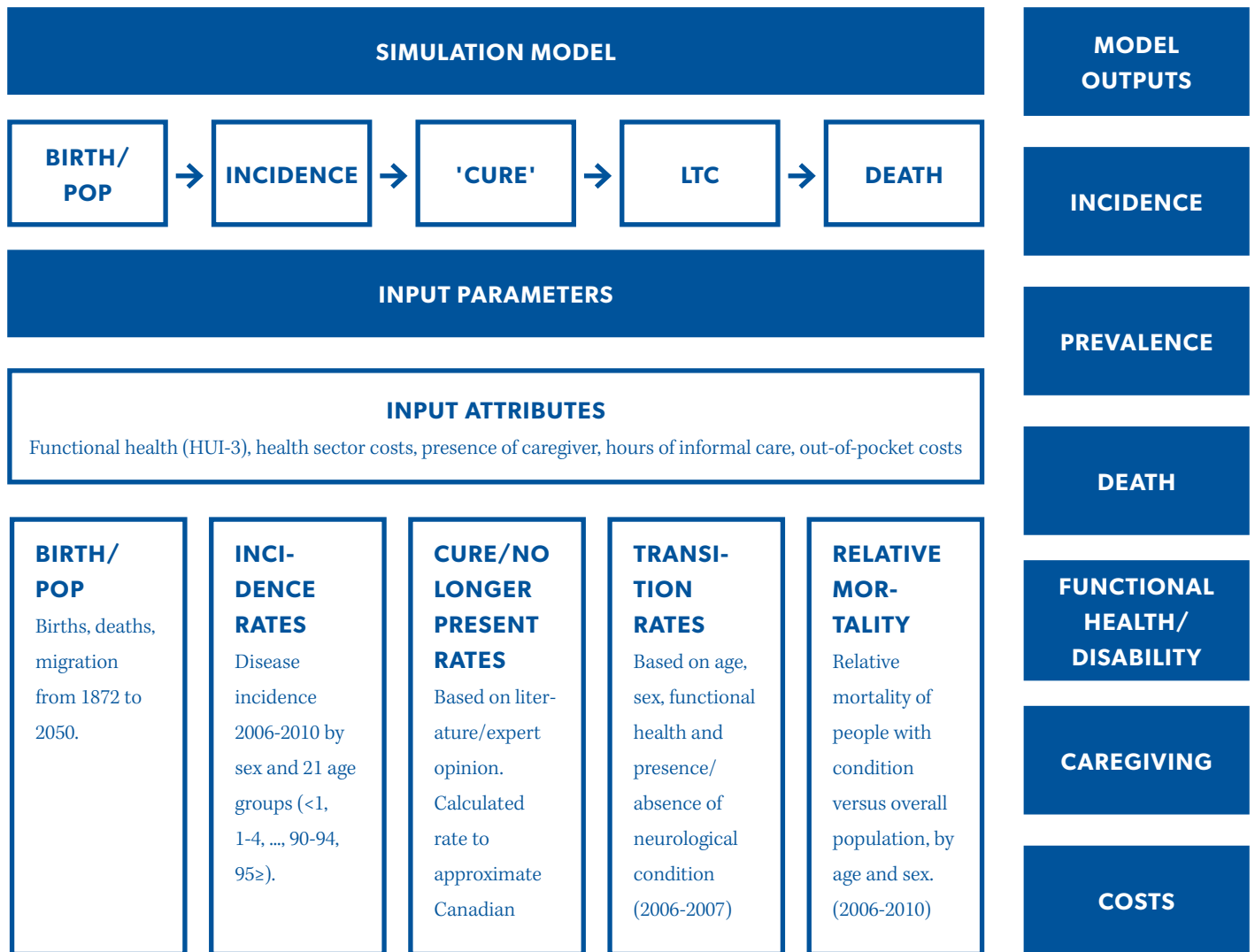
- *Synthesis*: capitalized on new data and new findings of incidence, prevalence, mortality and impacts of dementia, and consolidated these to give a current population-level picture.
- *Projections*: projected current population-level picture into future given what we know/anticipate about population demographic change (aging) in Canada.

- *Enhanced Surveillance*: Capitalizing on, but also enhancing new Canadian epidemiologic data on dementia.
- *Planning*: consolidate our understanding of population health burden of dementia in Canada and inform future health planning.
- *Platform*: for future applications of these models to examine assumptions and 'what if' scenarios' and forecast the population health and economic impacts of alternatives.

Halfway technologies refer to treatments that prolong survival without curing the condition, perhaps enabling individuals to survive to later stages of the condition. Future simulations could examine these treatments to determine if they increase health care costs. Costs may also be affected in future by changes in the stage at which individuals with cognitive concerns present to healthcare practitioners. Greater public awareness, the availability of treatments, professional attention to earlier identification of dementia and more widespread diagnostic work-up for cognitive concerns can increase health care costs. Simulation studies need to examine the impact of earlier and repeated neuroimaging, more widespread adoption of PET scanning, and CSF assays that together prolong therapy with new pharmaceuticals, immunotherapy and other treatments. That is, these increasingly adopted clinical assessments can result in earlier use of treatments without curing or stopping the progression of dementia (The Gerontology Society of America Workgroup on Cognitive Impairment Detection and Earlier Diagnosis, 2015).

**FIGURE 6**

CANADIAN NATIONAL POPULATION HEALTH STUDY OF NEUROLOGICAL CONDITIONS:  
SIMULATION MODEL  
(Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)

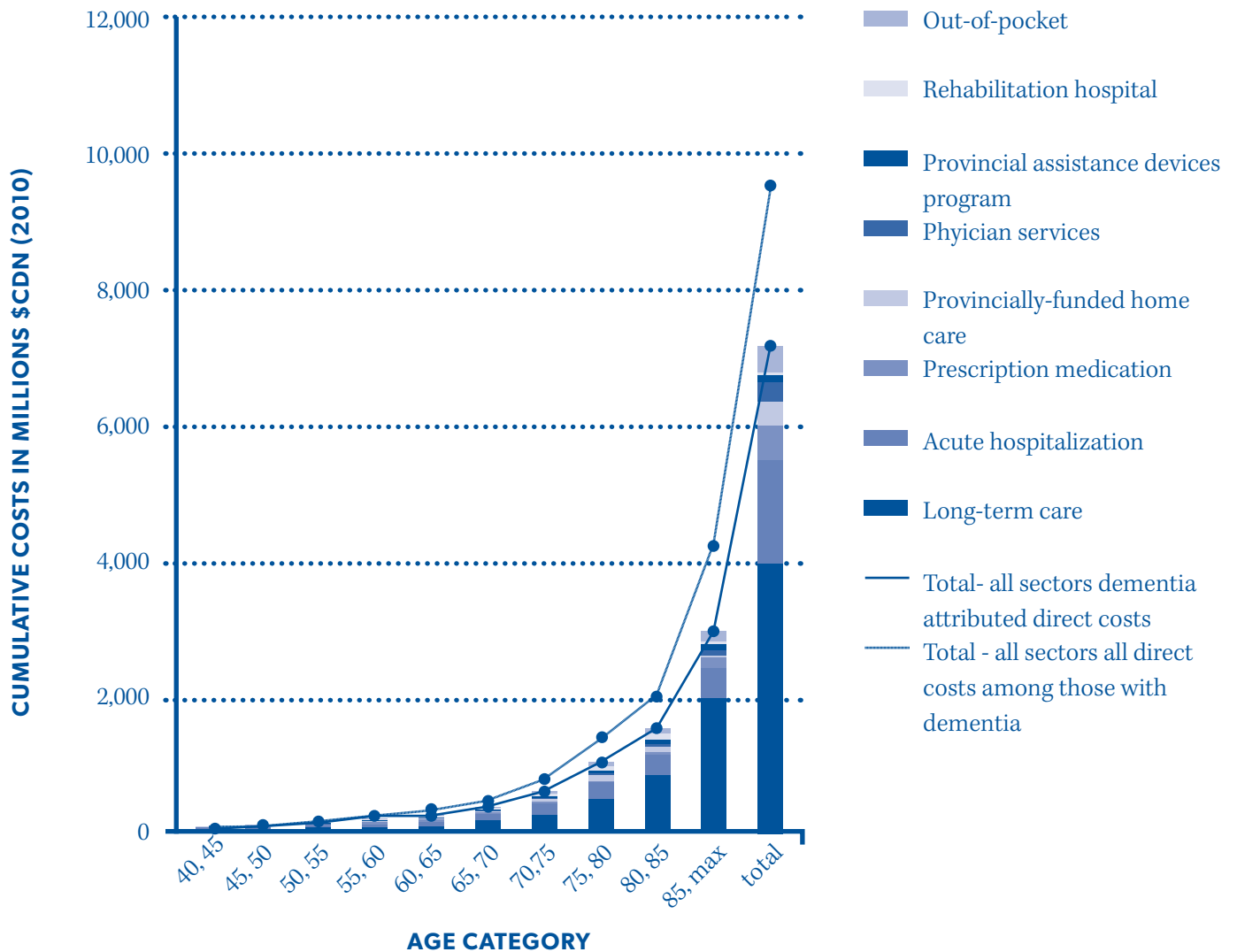


Source:  
National Population Health Study of Neurological Conditions. Personal Communication with Christina Bancej. January 2015.

**FIGURE 7**

PROJECTED DIRECT HEALTH CARE SYSTEM COSTS OF DEMENTIA\* BY SECTOR AND AGE CATEGORY, CANADA, 2011

(Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)



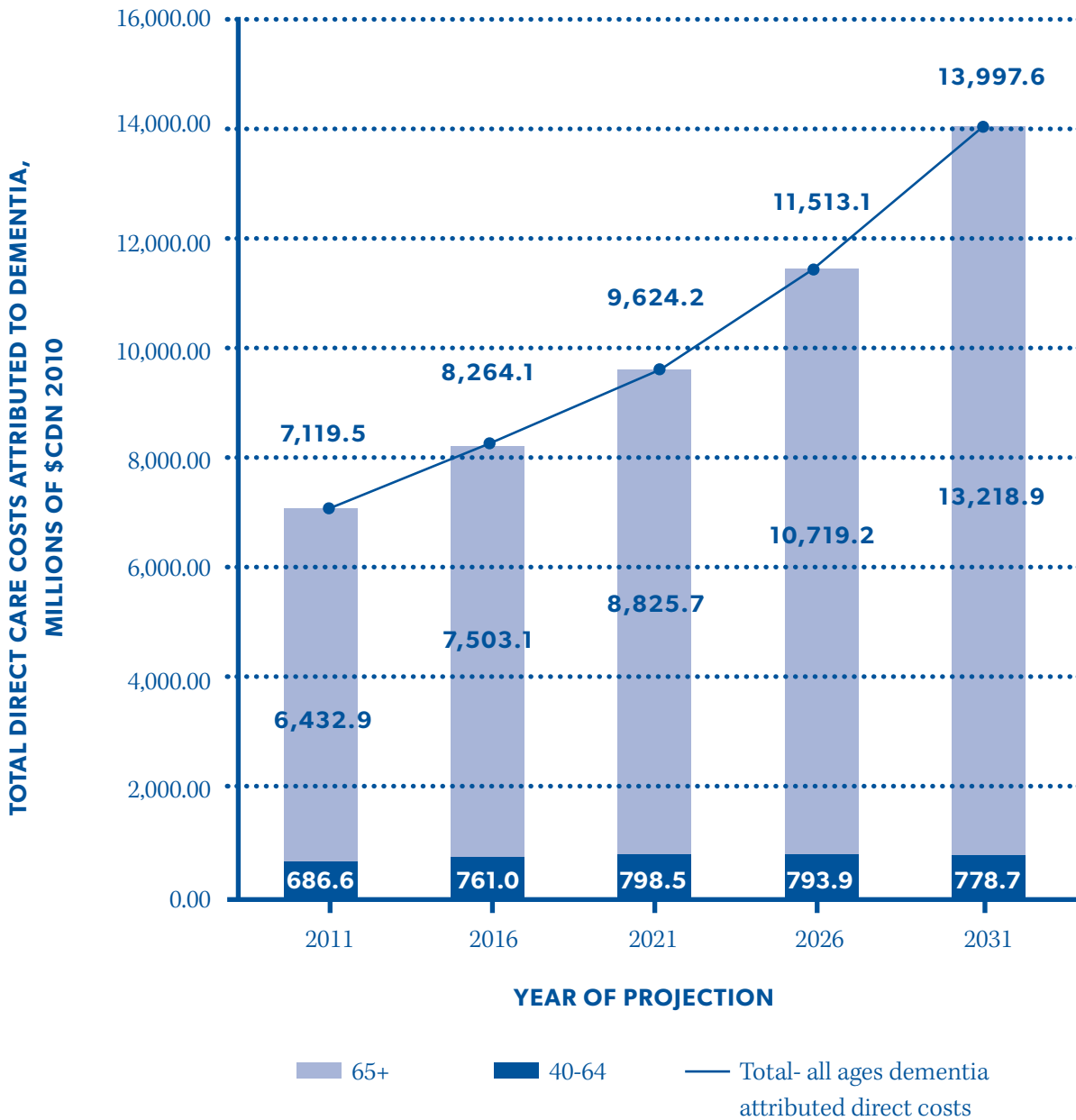
\*Note = Data do not include out of pocket caregiving costs (Figure 9)

Source:

Bancej C, Tu K, Reimer K, Fines P, Zycki A, Green D, Sutherland J, Garner R, Manuel D, Wall R, Bernier J. Current and projected direct and informal care costs among Canadians diagnosed with Alzheimer’s Disease and other dementias – A microsimulation study. Ottawa. Public Health Agency of Canada. Working Document. 2015.

**FIGURE 8**

PROJECTED TOTAL DIRECT HEALTHCARE SYSTEM COSTS ATTRIBUTED TO DEMENTIA\*, BY AGE CATEGORY (ONSET <65 YEARS VS ONSET >=65 YEARS) AND YEAR, CONSTANT \$CDN 2010 (Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)



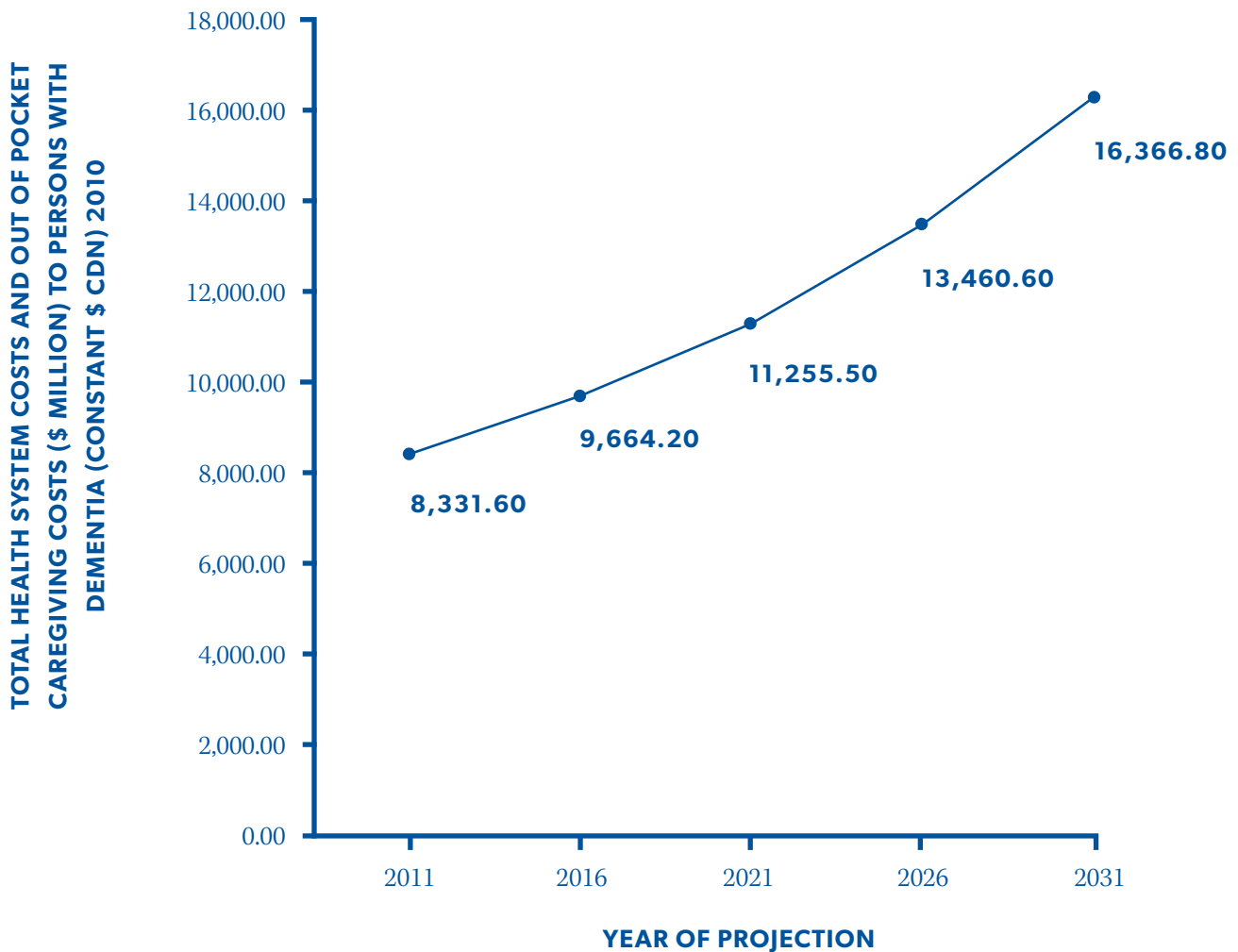
\*Note = Data do not include out of pocket caregiving costs (Figure 9)

Source:

Bancej C, Tu K, Reimer K, Fines P, Zycki A, Green D, Sutherland J, Garner R, Manuel D, Wall R, Bernier J. Current and projected direct and informal care costs among Canadians diagnosed with Alzheimer’s Disease and other dementias – A microsimulation study. Ottawa. Public Health Agency of Canada. Working Document. 2015.

**FIGURE 9**

PROJECTED TOTAL HEALTH SYSTEM COSTS AND OUT OF POCKET CAREGIVING COSTS (\$MILLION) TO PERSONS WITH DEMENTIA, CONSTANT \$CDN 2010, 2011 TO 2013  
(Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)



Source:

Bancej C, Tu K, Reimer K, Fines P, Zycki A, Green D, Sutherland J, Garner R, Manuel D, Wall R, Bernier J. Current and projected direct and informal care costs among Canadians diagnosed with Alzheimer’s Disease and other dementias – A microsimulation study. Ottawa. Public Health Agency of Canada. Working Document. 2015.

# 15.0 Recommended 2015 Alzheimer Society Messages about Monetary Costs

After discussing the review by Grignon et al (2015) and the findings from the National Population Health Study of Neurological Conditions (Bancej et al 2015), the expert panel recommends that the Alzheimer Society use the following statements about the present and future monetary costs of dementia in Canada using the National Population Study of Neurological Conditions as the basis for the cost estimates:

## CHALLENGES IN ESTIMATING DEMENTIA MONETARY COSTS

In estimating the monetary costs entailed in caring for persons with dementia, studies should explicitly identify in their analyses what costs are included (such as direct, indirect/informal and intangible costs), who incurs them (such as the health care system, patients and family members) and what monetary values are assigned to personnel and other resources in the community caring for persons with dementia compared with others who do not have dementia. While there is unavoidable uncertainty in estimating and projecting the costs involved in the treatment and management of dementia, informal caregiving should be counted among such costs.

## CURRENT ESTIMATES AND PROJECTIONS OF MONETARY COSTS OF DEMENTIA IN CANADA

According to the microsimulation analysis of the National Population Health Study of Neurological Conditions, total health care system costs and out of pocket costs of caregiving for people

with dementia were \$10.4 billion in 2016, and are projected to double by 2031 (Figure 9 and Table 4 – Note: Table 4 assumes a straight line from \$8.3 billion in 2011 to \$16.0 billion in 2031 and the numbers are interpolated with this assumption. Figure 9 shows the simulation model produced a curved line below the straight line, hence a lower estimate of \$10.3 billion for 2016). The costs for those with dementia are estimated to be five and one-half times greater than for those who are dementia-free. Long-term care and home care are the largest contributors to direct costs. In addition, the estimated 19.2 million hours of informal unpaid caregiver time in 2011 (conservatively valued at \$1.2 billion) is projected to double by 2031.

Demographic trends suggest that the costs associated with those living with dementia and their caregivers will increase rapidly unless there are significant reductions in the incidence of dementia.



# 16.0 Generating Estimates of Dementia Prevalence and Monetary Costs in Canada's Provinces

Efforts to better understand the prevalence, incidence and costs of dementia at the provincial level depend on the accessibility of appropriate data sources. In Ontario, the Institute for Clinical Evaluative Sciences (ICES) has access to health-related administrative data. The Ministry of Health and Long-Term Care supports a program called the “Applied Health Research Question” to support health research and knowledge translation to benefit the Ontario health system. The Alzheimer Society of Ontario took advantage of this opportunity to collaborate with ICES scientists on the development of a data set focusing on community-dwelling older adults (aged 66+) with physician-diagnosed dementia. The report covers a six-year period, from 2007-2012 (Bronskill et al 2015). The data compares the population of older people with and without dementia in terms of demographic characteristics, health system costs, comorbidities and health service utilization. In addition to increasing the understanding of the characteristics and needs of persons living with dementia, the data will also be disaggregated by geographic region to enable a more robust evaluation of the delivery of programs and services.

A take-home message from the Population Health Expert Panel is that many provinces now have in-province expertise in analyzing their provincial health administrative databases (Ng et al 2015, Kosteniuk et al 2015). Therefore, provincial Alzheimer Societies should request their provincial governments to use their provincial administrative databases to produce estimates of dementia prevalence and monetary costs for their province. The Societies should encourage collaboration between

provinces to develop consistent data algorithms that could be used to compare small area variation across geographic jurisdictions and across different patient groups over time.

The Public Health Agency of Canada should use the POHEM Neurological Model to produce provincial estimates of dementia prevalence and monetary costs. Data from the National Population Study of Neurological Conditions would be the main input data for the POHEM Neurological Model simulation analyses.

The Public Health Agency of Canada, in collaboration with provincial and territorial ministries of health, has developed the first national case definition that will be used to consistently report the epidemiology of Alzheimer's disease and other dementias (prevalence, incidence and all-cause mortality) among Canadians aged 65 years and older. Data will be disaggregated by sex, age group, fiscal year and province or territory. Annual reporting of these data is expected to begin in 2017/18. Many provinces now have in-province expertise in analyzing the provincial health administrative databases (Ng et al 2015, Kosteniuk et al 2015).

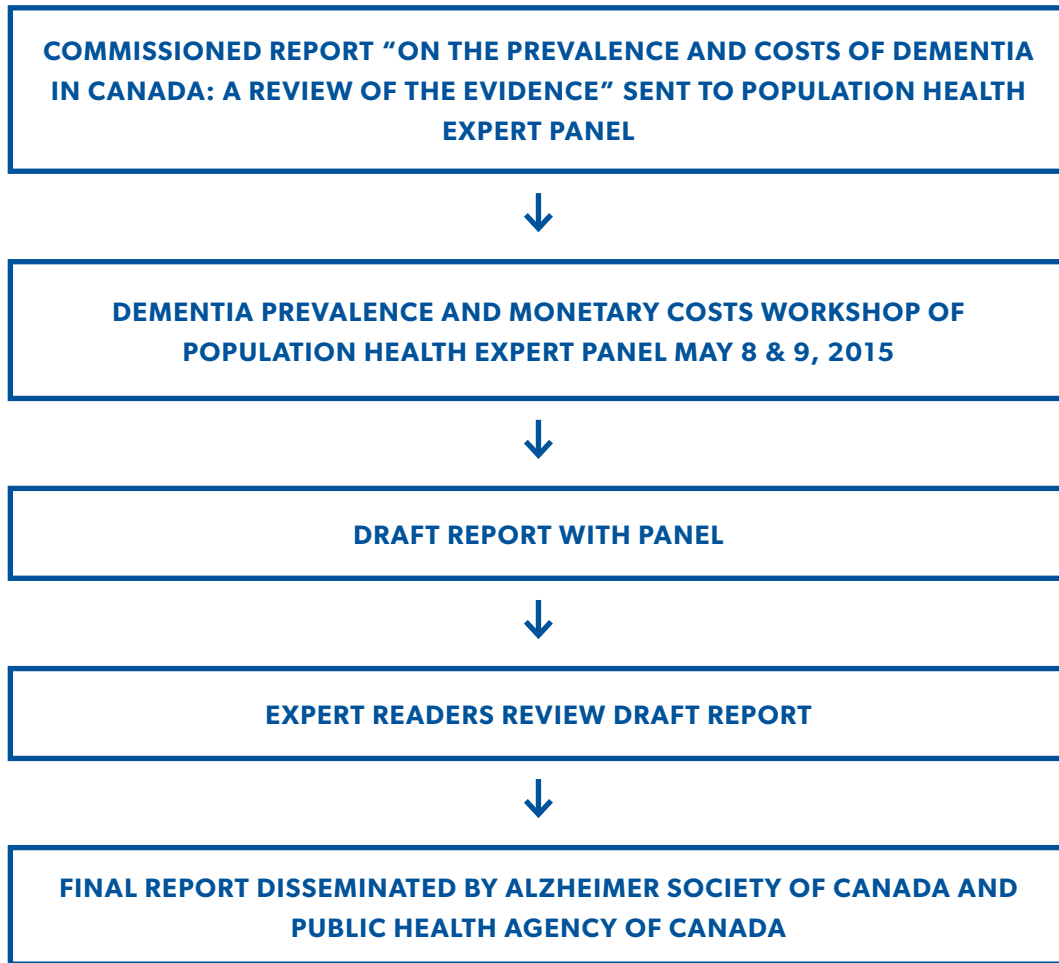
The Population Health Expert Panel strongly supports the Canadian Institute for Health Information's interest in generating reports on dementia. Ontario, Manitoba, Saskatchewan, Alberta, British Columbia are all interested in linked data from different health administrative data sources.

# 17.0 Production of this Report on Dementia Prevalence and Monetary Costs

The Alzheimer Society of Canada is viewed by both governmental and non-governmental organizations as the “place to go” to obtain estimates on prevalence and costs of dementia. Thus, the Society embarked on a process to generate the best information available to report to the media, public and policy makers. This Report has the following feature: a Population Health Expert Panel formed of members of Canadian and international research teams who were brought together with policy makers and researchers from governments and the Alzheimer Society. These individuals were asked to assist the Alzheimer Society of Canada in deciding on 1) Single dementia prevalence and monetary cost estimates for Canada that can be used by the Alzheimer Society of Canada and by provincial and regional Alzheimer Societies, 2) Advice to provinces and territories of Canada on how to derive estimates using national estimates, and, 3) Priorities for future research. Figure 10 outlines the steps taken in the production of this report on dementia prevalence and monetary costs in Canada.

**FIGURE 10**

PROCESSES USED IN PREPARING THE REPORT OF THE POPULATION HEALTH EXPERT PANEL OF THE ALZHEIMER SOCIETY OF CANADA  
(Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)



# 18.0 Summary

This Report made recommendations about dementia prevalence and monetary cost estimates and projections for Canada. Methodological issues in interpreting these estimates were identified. Users of the Report should acknowledge the unavoidable uncertainty associated with estimating and projecting prevalence and monetary costs of dementia. Methods of estimating provincial dementia prevalence and monetary costs were recommended. This Report identified knowledge gaps for future research priorities. The media, the public and policy makers will hopefully find this Report useful.

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# Box 1: Estimating Monetary Costs: Perspective, Scope and Evaluation

## 1 PERSPECTIVE

Costs can be measured from the following perspectives: persons with dementia, their families, or society. Each choice has advantages and limitations (Table 5). The Alzheimer Society of Canada prefers the societal perspective, as dementia involves costs that go well beyond any single payer even in a publicly funded health care system. Both the total cost in the population and cost per individual case of dementia are of interest to the Alzheimer Society. For example, calculating costs at each stage of severity for individual patients and for the whole Canadian population could help the public to understand the significant impact of the progressive nature of dementia.

**TABLE 5**

HOW PERSPECTIVE INFLUENCES WHICH COSTS ARE COUNTED IN A COST ANALYSIS  
(Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)

Costs	Perspectives			
	Societal	Insurer/Payer	Employer	Patient/Client
Direct Medical	Yes	Yes	Yes	Yes
Direct non-medical (e.g., transportation, day care)	Yes	No	No	Yes
Indirect/Informal (e.g., time lost from work)	Yes	No	Yes	Yes
Intangible (e.g., pain and suffering)	Yes	Yes**	No	No

Source:

Dunet DO. CDC Coffee Break: Introduction to Economic Evaluation. Centers for Disease Control. Atlanta, January 2012.

# Box 1: Estimating Monetary Costs: Perspective, Scope and Evaluation

## 2 SCOPE

To be consistent with the societal perspective in determining the costs of dementia, cost estimates should consider including direct, indirect/informal as well as intangible costs.

*Direct* costs are those that are measured based on observed prices (such as bills to a third party) whereas indirect/informal costs (such as cost of informal care) are not observed and must be imputed: imputation that requires assigning a price to an activity that has no market (or administrative) price. The economist conducting the imputation must choose between valuing the activity either at its replacement cost (how much it would cost to get the same service from a formal provider charging a fee?) or at its opportunity cost (what is the value of the time the person providing the service for free must forgo to provide care to the person with dementia?).

In the case of dementia, the *indirect/informal* costs are large, as most persons living with dementia in the community receive informal, and generally unpaid, care from relatives.

*Intangible* costs reflect the loss in utility or well-being of persons with dementia and their care-givers. These, too, must be imputed, for example using measures of the loss of quality-adjusted life years caused by dementia. Such costs are likely to be very large and the estimates themselves subject to question.

# Box 1: Estimating Monetary Costs: Perspective, Scope and Evaluation

## 3 ATTRIBUTING COSTS TO DEMENTIA

The preferred approach involves the use of statistical models to estimate incremental costs – that is, the cost of care for otherwise identical individuals, one with dementia and one without. The approach typically involves the use of some version of regression analysis in which the analyst controls for (or standardizes for) the determinants of health care spending by estimating total health care costs as a function of age and other relevant characteristics, including whether or not demented. The estimated impact of “dementia” is then a measure of the incremental costs associated with that condition after taking other factors that influence costs into account.

A key question in such estimation is which variables to include – that is, what should the analyst standardize in the comparison. For instance, Hurd et al. (2013) standardized for age, sex, income and insurance, but not for proximity to disability or death, whereas Yang et al. (2012) did standardize for these two latter variables. As a result, Yang et al. estimate a much smaller annual cost of dementia than Hurd et al.: not standardizing for proximity to death and disability yields an estimate five times greater in Hurd et al. than in Yang et al. (The comparison is also made difficult by the fact that Yang et al. estimated lifetime cost from age 65 whereas Hurd regressed annual cost directly; here we use lifetime cost divided by life expectancy at 65 to produce an equivalent annual cost by Yang et al.)

The discrepancy is no mere technical difference: it is about whether we believe that dementia actually causes disability and death or whether it is simply associated with them. In the first case, Hurd et al. are right, in the latter, Yang et al. are. The truth probably lies somewhere between these two extremes. On the one hand, people with dementia are much more likely to have falls, urinary tract infections, pulmonary infections and cardiovascular problems than people of the same age and gender without dementia (Toot et al. 2013, Prince et al 2014a) which implies that dementia shortens life and causes disability. Overall, current scientific evidence does not allow us to tell how much disability, and proximity to death should be used in the standardization exercise to estimate the direct costs of dementia Giebel et al. (2015).

The case of indirect cost is even more complex. Two decisions need to be made: how to estimate the volume of informal, unpaid activity involved in the treatment of dementia, and how to value each unit of informal activity. Measuring the volume of activity is complex because caregiving activities are recorded through surveys of self-reported time use and caregiving activities are valued based on a single average cost per unit of time. However, caregivers multitask so it is not easy to separate caregiving from other activities. Nor is it certain that the total cost of caregiving lies in a linear relationship with the amount of time providing care. Finally, the unit cost can be based on replacement or on opportunity costs, yielding very different results.

Janice Keefe has documented the array of monetary costs of persons living with dementia and their caregivers (Keefe 2011). The model outlined in Figure 11 is based on her research and was used in the simulation analysis of the National Population Health Study of Neurological Conditions (Public Health Agency of Canada 2014c). If these informal costs such as caregiving and multi-tasking are available from community surveys, then estimates of average cost per unit of time are possible to generate.

One last issue with attributing costs to dementia is that of stages of dementia: the preceding discussion has concerned the average cost of dementia over all people with the disease. However, it is well known that costs vary significantly with stages of dementia. As shown in Figure 12, the Canadian Study of Health and Aging (1994) reported data showing that the percentage of persons with dementia in institutional care increases for each stage of mild, moderate and severe dementia. The CSHA provided these first Canada-wide “institution” and “community” cost estimates. Figure 13 presents the results, showing how costs of dementia increase with its severity.

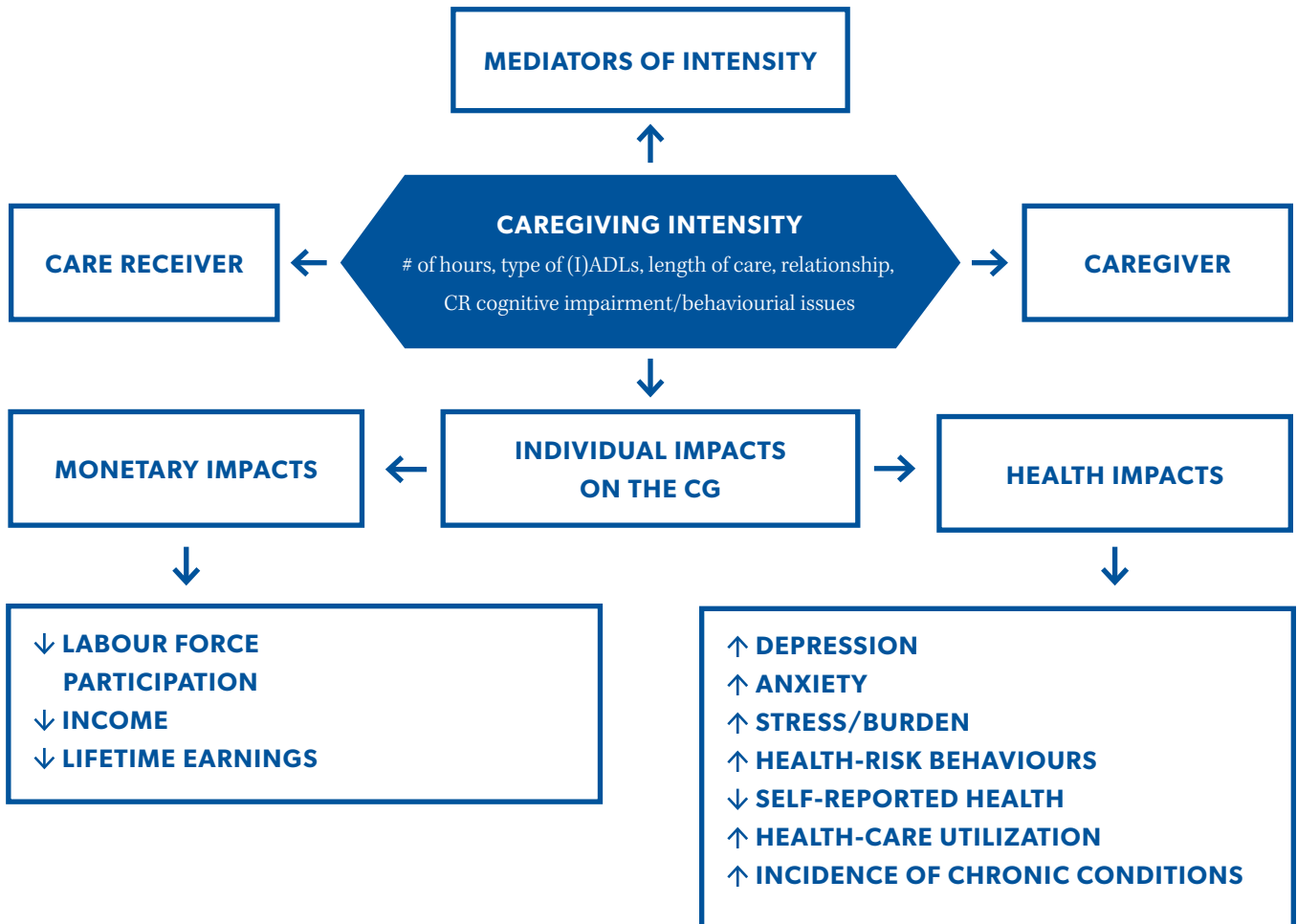
The type of housing required for different stages of dementia severity (e.g. transition from home to a care facility) can be used to estimate the cost of care (Figure 13). With the exception of the CSHA (Hux et al, 1998), cost data in Canada for levels of severity of dementia have not been generated at the population level through community surveys. However, administrative data can fill this gap. The percentage of persons at different stages of

dementia severity by each living arrangement can be used to estimate monetary costs of dementia (Hirdes et al) (Figure 14). The data in Figure 14 have been assembled from a number of Canadian studies that have estimated these costs using interRAI clinical databases (Maxwell et al 2013, Vu et al 2014, Maxwell et al poster, Hirdes JP et al 2011, Bronskill et al 2015, Strain et al 2011).

**FIGURE 11**

**COST VALUATION: INFORMAL COSTS OF CAREGIVING AND MULTI-TASKING**

(Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)

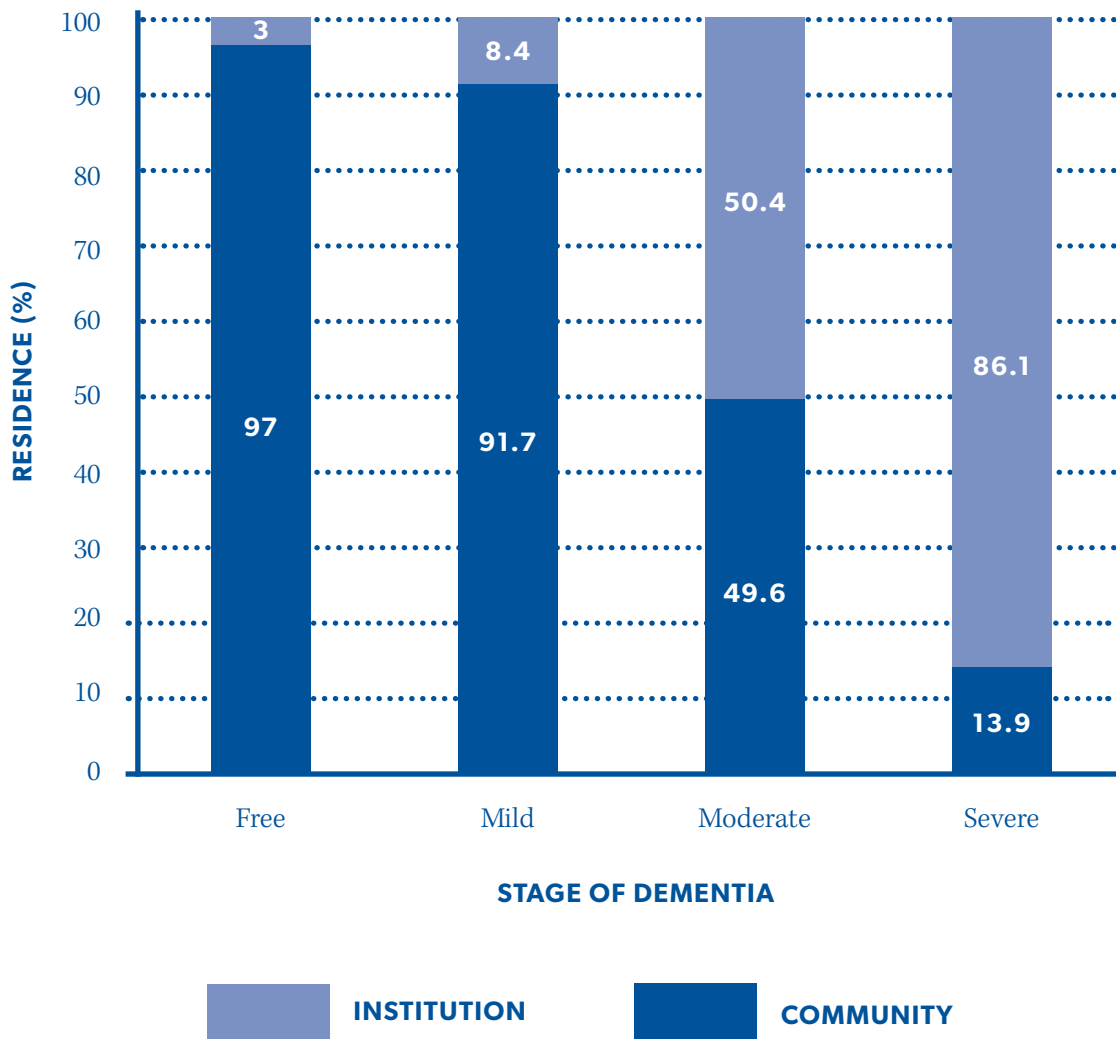


Source: National Population Health Study of Neurological Conditions. Personal Communication with Christina Bancej, January 2015.



**FIGURE 12**

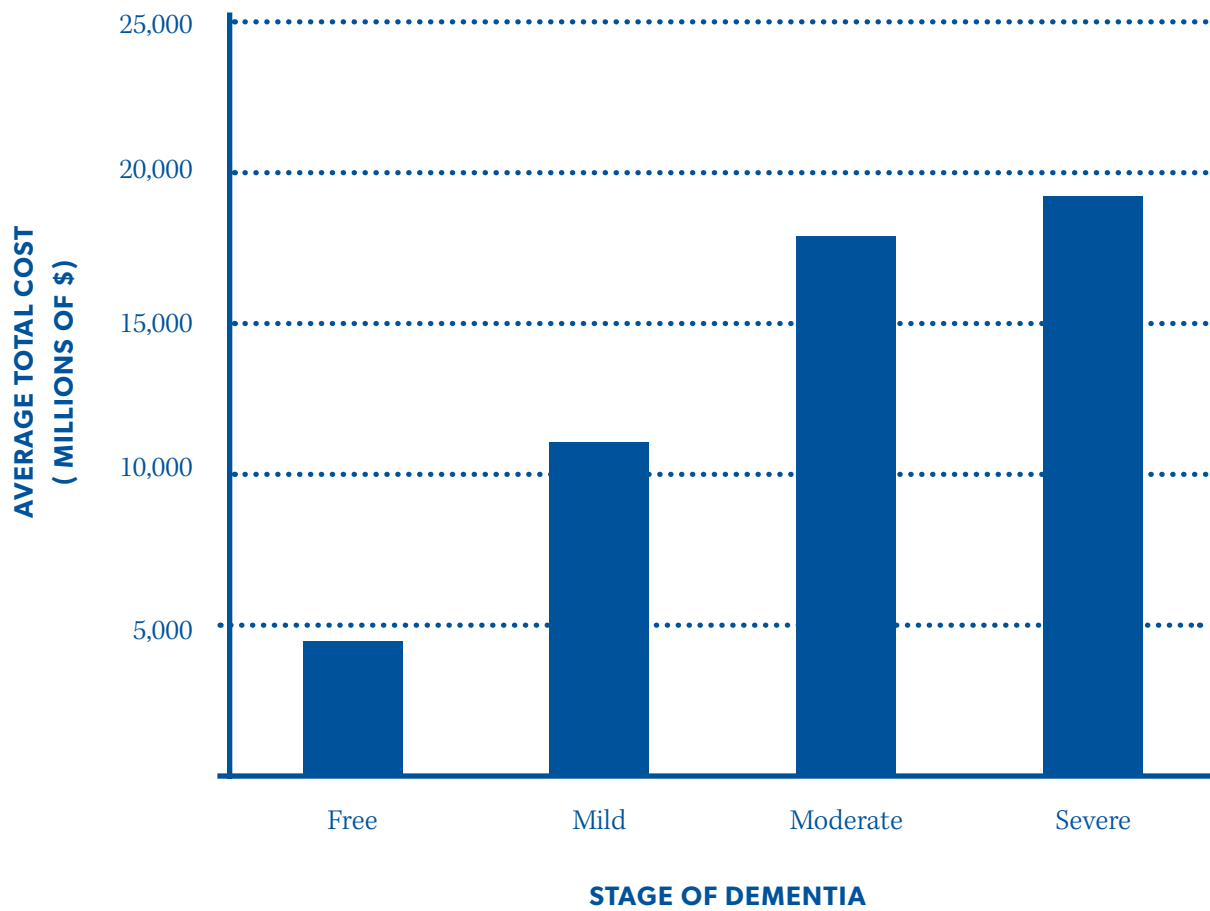
PERCENTAGES OF RESIDENTS WITH DEMENTIA LIVING IN THE COMMUNITY VERSUS IN INSTITUTIONS BY STAGE OF DEMENTIA, CANADA, 1991  
(Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)



Source:  
Canadian Study on Health and Aging: <http://www.csha.ca/>

**FIGURE 13**

COST OF DEMENTIA BY STAGE OF SEVERITY, CANADA, 1991  
(Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)

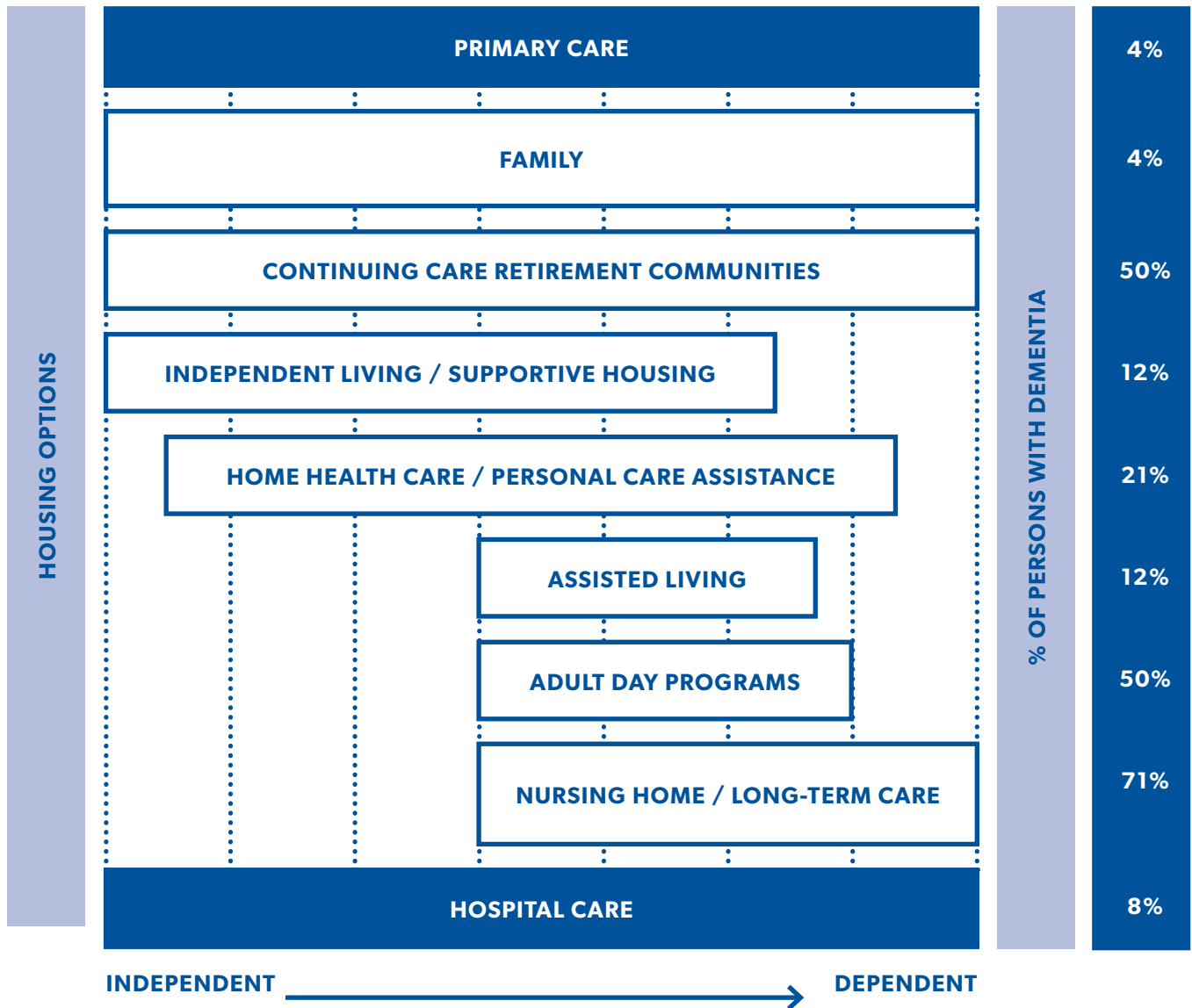


Source:  
Canadian Study of Health and Aging: <http://www.csha.ca/>

**FIGURE 14**

COST VALUATION: COMMUNITY-WIDE HOUSING OPTIONS FOR OLDER ADULTS REQUIRING CONTINUING CARE BY LEVEL OF DEPENDENCY AND PERCENT OF PERSONS WITH DEMENTIA IN EACH TYPE OF CARE

(Prevalence and Costs of Dementia in Canada, Alzheimer Society of Canada, Toronto, 2016)



Sources:

Prevalence Estimate from: Maxwell et al 2013, Vu et al 2014, Maxwell et al poster, Hirdes JP et al 2011, Bronskill et al 2015, Strain et al 2011.

# Appendix A

## ON THE PREVALENCE AND COST OF DEMENTIA IN CANADA: A REVIEW OF THE EVIDENCE.

Working Paper available from Michel Grignon, Centre for Health Economics and Policy Analysis, Department of Clinical Epidemiology and Biostatistics, Faculty of Health Sciences, McMaster University, Hamilton, Ontario, Canada

# Appendix B

ALZHEIMER'S AND OTHER DEMENTIAS IN CANADA, 2011 TO 2031: A MICROSIMULATION POPULATION HEALTH MODELING (POHEM) STUDY OF PROJECTED PREVALENCE, HEALTH BURDEN, HEALTH SERVICES, AND CAREGIVING USE

<https://pophealthmetrics.biomedcentral.com/articles/10.1186/s12963-016-0107-z>

# Appendix C

## POPULATION HEALTH EXPERT PANEL BIOGRAPHIES

**CHRISTINA BANCEJ, PHD (CO-CHAIR)** is an epidemiologist and managed the Population Health Modelling Section in the Social Determinants and Science Integration Directorate at the Public Health Agency of Canada. Her Ph.D. is from McGill University, where she completed graduate training (MSc, PhD) with the Department of Epidemiology and Biostatistics. Since joining the Laboratory Centre for Disease Control (Health Canada/Public Health Agency of Canada) in 1997, Dr. Bancej has contributed to surveillance, research, policy and program planning, implementation and evaluation working in collaboration and partnership with stakeholders on a range of determinants, risk factors and federal policy priority issues from maternal-child health, cancer screening, non-communicable disease surveillance, modelling population health, disease and economic impacts, outbreak preparedness and response, and immunization. Currently, a key focus for her is to strengthen the emphasis on science to policy, including enhancing linkages between science capacity and social determinants, and the emphasis on medium-term considerations and initiatives enabling increased understanding, anticipation and response to critical emerging issues in public health. As a principal investigator of the microsimulation component of the 4-year National Population Health Study of Neurological Conditions, an initiative of the Government of Canada, she worked in partnership with Statistics Canada, an expert working group, study investigators and people living with or caring for someone living with a neurological condition across Canada to develop models of the population health and economic impacts of neurological conditions, including Alzheimer's and other dementias, to inform future population health planning in Canada.

**LARRY CHAMBERS, PHD (CO-CHAIR)** is Scientific Advisor to the Alzheimer Society of Canada. He maintains appointments with the Bruyère Research Institute, as well as with the University of Ottawa, McMaster University (Professor Emeritus), York University, the Institute for Clinical Evaluative Sciences and the Nursing Best Practice Research Centre. He was a co-investigator for the Canadian Study of Health and Aging and presently an investigator with the Canadian Longitudinal Study on Aging. The 2012 Canadian Institutes of Health Research – Canadian Medical Association Journal Top Achievements in Health Research Award was awarded to Dr. Chambers and his colleagues for the Cardiovascular Health Awareness Program which is now a demonstration project with the Quebec Strategy for Patient-Oriented Research Support Unit. He is author or co-author of over 170 peer-reviewed publications in scientific journals. Dr. Chambers is a Fellow with the Canadian Academy of Health Sciences, a Fellow with the American College of Epidemiology, and Honourary Fellow with the Faculty of Public Health of the United Kingdom. He is also chair of the Research Committee of the Health Charities Coalition of Canada.

**MATTHEW BAUMGART, BA** is the Senior Director of Public Policy for the Alzheimer's Association. The work under his purview includes state government affairs, policy development, global policy efforts, and public health, including the Healthy Brain Initiative project with the Centers for Disease Control and Prevention (CDC). In his policy development role, Mr. Baumgart assists with the writing of the Association's annual *Facts and Figures* report, manages all work on the economics of Alzheimer's disease, and serves as an in-house expert on epidemiological data on dementia. Prior to joining the Association, Mr. Baumgart worked for nearly 18 years in the United States Senate. Most recently, he was Legislative Director for Senator Barbara Boxer of California, where he supervised the legislative staff, managed all of the Senator's legislative activities, and was her chief legislative strategist. Prior to working for Senator Boxer, Mr. Baumgart worked for over 10 years for then-Senator Joseph R. Biden, Jr. of Delaware, primarily as Legislative Assistant for social policy issues, including health care. Mr. Baumgart is a native of Seattle, and has a degree in Communications, with a second major in Political Science, from Washington State University in Pullman, WA.

**JENNIFER BETHELL, PHD** is a Postdoctoral Research Fellow at the Toronto Rehabilitation Institute, University Health Network. Her PhD is from the University of Toronto, and she carried out her graduate work at St. Michael's Hospital and the Institute for Clinical Evaluative Sciences (ICES). Following her PhD, Dr. Bethell worked for the Alzheimer Society of Canada, with the Alzheimer Society Research Program. Currently, her postdoctoral work is a project to elicit dementia research priorities from Canadians, including those with dementia, their friends, family and caregivers, and health and social care providers.

**CAROL BRAYNE, MD** is Professor of Public Health Medicine in Department of Public Health and Primary Care in the University of Cambridge. She is a medically qualified epidemiologist and public health academic. She graduated in medicine from the Royal Free Hospital School of Medicine, University of London and went on to train in general medicine. After gaining membership she moved on to training in epidemiology with a Training Fellowship with the Medical Research Council. The research area for this Fellowship was ageing and dementia. Since the mid eighties her main research area has been longitudinal studies of older people following changes over time in cognition, dementia natural history and associated features with a public health perspective. She is lead principal investigator in the group of MRC CFA Studies which have informed and will continue to inform national policy and scientific understanding of dementia in whole populations. She is Director of the Cambridge Institute of Public Health at the University of Cambridge and has played a lead role for teaching and training programmes in epidemiology and public health for under and postgraduates at the University of Cambridge. She is a Fellow of the Academy of Medical Sciences.

**ADELINA COMAS-HERRERA, MSC** is Assistant Professorial Research Fellow at the Personal Social Services Research Unit at the London School of Economics and Political Science. She is the academic project manager of the “Modelling Dementia” (MODEM) research project, a four year project which aims to estimate the impact, in terms of costs and quality of life, of making interventions that are known to work for people with dementia and their carers more widely available by 2040. Ms. Comas-Herrera has previously worked on making projections of future long-term care expenditure for the UK and developed a methodology that is used by the European Commission (DG ECFIN) to make comparable projections of public long-term care expenditure by the European member states. She has also worked on long-term care financing, evaluating the potential role of private insurance and private/public partnerships in long-term care financing.

**HOWARD FELDMAN, MD** is a neurologist with special expertise in cognitive disorders and the dementias. He is the Director of the UBC Hospital Clinic for Alzheimer’s disease and Related Disorders and is a Professor of Neurology, at the University of British Columbia. Since 2012 he has served as the Executive Associate Dean Research for the UBC Faculty of Medicine. He has authored or coauthored over 150 peer reviewed publications among total publications of > 390 and has H Index > 50. His career contributions have been profiled in *Lancet Neurology* in 2007, and in 2014 was named by Thomson Reuters as a ‘highly cited’ neuroscientist (2002-2012) and among ‘the world’s most influential scientific minds’. He has been appointed as Fellow of the Canadian Academy of Health Sciences and the American Academy of Neurology in 2008. He currently serves as the inaugural Fisher Family and Alzheimer Society of British Columbia Endowed Professorship for Research in Alzheimer’s disease.

**SUDEEP GILL, MD MSC** is an Associate Professor in the Departments of Medicine and Public Health Sciences at Queen’s University. He is a Scientist at the Institute for Clinical Evaluative Sciences where he has conducted health services research on patterns of care and appropriate medication prescribing for older individuals with Alzheimer disease and related dementias.

**MICHEL GRIGNON, PHD** who was named director of Centre for Health Economics Policy and Analysis on Sept. 1, 2011, is a professor in the Department of Economics and the Department of Health, Aging and Society at McMaster University. He is editor-in-chief of the journal *Health Reform Observer – Observatoire des Réformes de Santé* and is also an adjunct scientist at the Institute for Health Economics in Paris, France. Before joining McMaster in July 2004, he worked at the Institut de Recherche, d’Etudes et de Documentation en Economie de la Santé (IRDES) in Paris. He was born in France, and obtained his Master’s Equivalent at the National School for Statistics and Economics in Paris, and his PhD at Ecole de Hautes Etudes en Sciences Sociales, also in Paris. Grignon has extensive experience at an international level in



research projects and activities in the areas of health economics, health-related policies, health insurance and aging. His current research projects cover a broad range of topics, including how an aging society impacts health care expenditures in Canada and in France. He is also involved in research examining inequities in health care utilization and health policy in Canada, as well as exploring equity and efficiency by using experimental economic methods for financing health care. Dr. Grignon's research interests include: financing and funding of health care and health insurance; the impact of aging on health care usage and expenditures; economics of health and health care and its distribution in populations; determinants and patterns of health care consumption and delivery of health care; and, econometric analysis of the impact of taxes on tobacco consumption in France.

**SARA GUILCHER, PT PHD** is an Assistant Professor at the Leslie Dan Faculty of Pharmacy, University of Toronto and Affiliate Scientist at the Centre for Research on Inner City Health, Li Ka Shing Knowledge Institute, St. Michael's Hospital. Recently, Dr. Guilcher worked as a Senior Researcher with the Canadian Population Health Initiative at the Canadian Institute for Health Information (CIHI). As a health services researcher and physical therapist, Dr. Guilcher's research interests relate to social epidemiology, health equity, disability and complex chronic conditions. Dr. Guilcher has a MSc in Physical Therapy from the University of Toronto, MSc in Psychology (Clinical) from Western University and PhD in Clinical Epidemiology- Institute of Health Policy, Management and Evaluation from the University of Toronto. During her doctoral training, Dr. Guilcher also completed two collaborative programs: (1) Ontario Training Collaborative Program in Health Services and Policy Research and (2) Collaborative Program in Women's Health.

**COLLEEN MAXWELL, PHD** is a Professor with the Schools of Pharmacy and Public Health & Health Systems, University of Waterloo, an Adjunct Scientist with the Institute for Clinical Evaluative Sciences (ICES), and an Adjunct Professor with Community Health Sciences, University of Calgary. She is a senior health services researcher with expertise in aging, frailty, continuing care and pharmacoepidemiology. Her research interests include the quality of care and pharmacotherapy of older vulnerable populations across the care continuum – particularly those with dementia, depression and related disorders. Dr. Maxwell is a past Board Member of the International Society for Pharmacoepidemiology, Canadian Association for Population Therapeutics and a current Board Member of the Canadian Society for Epidemiology and Biostatistics and the PROPEL Centre for Population Health Impact (University of Waterloo).

**IAN MCDOWELL, PHD** is an emeritus professor at the University of Ottawa. He was the principal investigator on the Canadian Study of Health and Aging and was on the advisory panel for the National Population Health Study of Neurological Conditions.

**GILLIAN MULVALE, PHD** is an Assistant Professor, Health Policy and Analysis in the DeGroote School of Business at McMaster University. Her research focus is on improving care coordination across health professions, sectors, and stages of the lifespan through the development of health policy and management frameworks that promote interprofessional, person and family-centred care, with applications in mental health and primary health care. Ms. Mulvale derives theoretical approaches from interdisciplinary training in health policy analysis, health economics and health research methods. In previous roles, Ms. Mulvale was a member of the Mental Health Commission's Mental Health Strategy team and co-authored *Toward Recovery and Well-being: a Framework for a Mental Health Strategy for Canada* and led the Canadian Foundation for Healthcare Improvement's *Healthcare Financing, Innovation and Transformation Initiative*.

**MARK OREMUS, PHD** is an Associate Professor in the School of Public Health and Health Systems at the University of Waterloo. He also holds a part-time appointment as an Associate Professor in the Department of Clinical Epidemiology and Biostatistics at McMaster University. Dr. Oremus is the Associate Scientific Director of the Canadian Longitudinal Study on Aging and an Associate Researcher at the Gilbrea Centre for Studies in Aging at McMaster University. He teaches epidemiology at the graduate and undergraduate levels. Dr. Oremus' primary research interests include aging and chronic disease, dementia, and Alzheimer's disease. He has conducted studies on willingness-to-pay for Alzheimer's disease medications, measuring quality-of-life in Alzheimer's disease, and the use of outcome measurement instruments in Alzheimer's disease drug trials. Dr. Oremus' other research interests include systematic reviews, population and public health from a life-course perspective, health policy and economics, and knowledge transfer. Dr. Oremus' held a Career Scientist Award from the Ontario Ministry of Health and Long-Term Care and he was the inaugural recipient of the Bernie O'Brien Postdoctoral Fellowship at McMaster University. He is Vice President of the Canadian Society for Epidemiology and Biostatistics and the Communications Officer for the International Joint Policy Committee of the Societies of Epidemiology.

**PARMINDER RAINA, PHD** is a Professor in the Department of Clinical Epidemiology and Biostatistics at McMaster University and an Associate Member, Faculty of Health Sciences, Department of Psychiatry and Behavioural Neurosciences. He specializes in the epidemiology of aging with emphasis on developing the interdisciplinary field of geroscience to understand the processes of aging from cell to society. He has expertise in epidemiologic modeling, systematic review methodology, injury, and knowledge transfer. He holds a Tier 1 Canada Research Chair in Geroscience and the Raymond and Margaret Labarge Chair in Research and Knowledge Application for Optimal Aging. He is the lead investigator of the Canadian Longitudinal Study on Aging. He has served as a Hamilton site lead investigator for Canadian Study of Health and Aging (population study of Dementia). He is one of the founding members of McMaster Optimal Aging Portal for Citizens and decision-makers. He is the Director of the recently established McMaster

Institute of Geroscience. Dr. Raina is one of the founding members of the Ontario Research Coalition of Aging Institutes/Centers funded by the Ontario Ministry of Health and Long-term Care.

**DUNCAN ROBERTSON, MD, FRCP, FRCPC, FACP** is a specialist in Internal Medicine from Victoria, BC, he was one of the first Canadian physicians recognized by the Royal College of Physicians and Surgeons of Canada as a Specialist in Geriatric Medicine. He previously held professorial appointments at the Universities of Alberta and British Columbia and at the Universities of Saskatchewan and Toronto where he was also Head of Geriatric Medicine. Dr. Robertson's clinical interest in dementing disorder dates from the 1970s and he has served as a member of the Board of the Alzheimer Society of British Columbia and the Council on Health Promotion of the British Columbia Medical Society. He currently serves as Senior Medical Director of Alberta's Seniors Health Strategic Clinical Network, Co-Chair of the Alberta Dementia Strategy and Action Plan Steering Committee and of the Primary Health Care and the Acute Care and Crisis Management Working Groups.

**PAULA ROCHON, MD, MPH, FRCPC** is a geriatrician and the vice-president of research at Women's College Hospital, which is fully affiliated with the University of Toronto. She is a senior scientist at Women's College Research Institute; a professor in the Department of Medicine and Institute of Health Policy, Management and Evaluation at the University of Toronto; and a senior scientist at the Institute for Clinical Evaluative Sciences. In July 2015 she was appointed as the inaugural Retired Teachers of Ontario Chair in Geriatric Medicine at the University of Toronto. Dr. Rochon's research career has focused on understanding the unique needs of older adults, particularly women, who make up the majority. In particular, her research explores how medical therapies impact the health of older adults with multiple conditions. Her work has contributed substantively to three areas of focus: the need for evidence to provide information that is more relevant to older adults, the exploration of strategies to reduce adverse drug events and to optimize drug therapy, and very specifically the impact of widespread use of antipsychotic therapy in older people. In 2013, she was elected to the Canadian Academy of Health Sciences.

**BYRON SPENCER, PHD** is Professor of Economics and Academic Director of the Statistics Canada Research Data Centre at McMaster University. He is also the Principal Investigator for the Canadian Research Data Centre Network. His research in recent years has centred around the SEDAP (Social and Economic Dimensions of an Aging Population) Research Program, whose purpose has been to gain a better understanding of the likely social and economic consequences of the inevitable aging of the population that will take place in Canada over the next few decades. Dr Spencer has published extensively on the impact of population change on the economy, on our social security system, and on both the future need for health care services as the population ages and the ways in which those needs could be met. In 2011

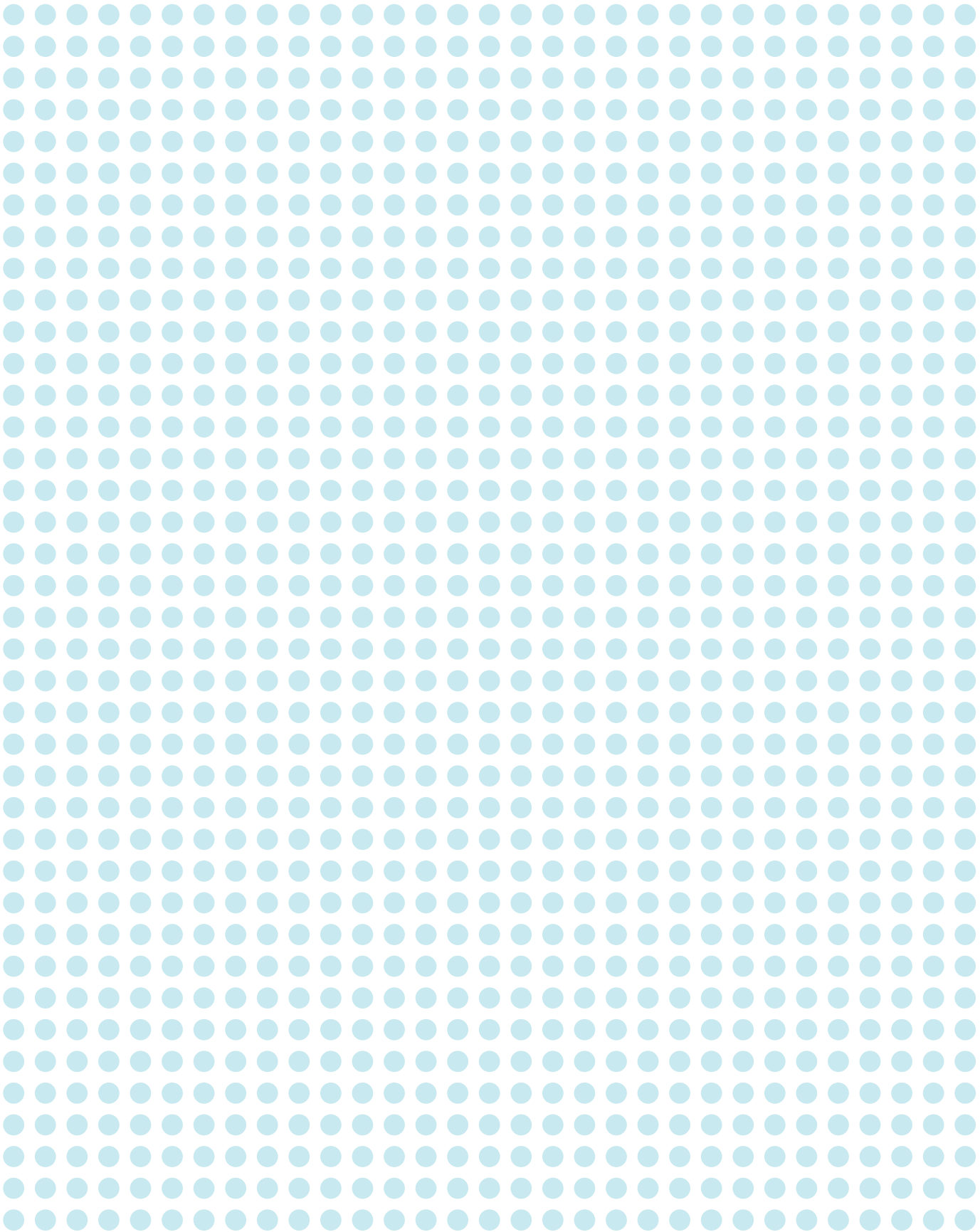
he and Frank Denton were awarded the *Vanderkamp Prize* for their paper "Age of Pension Eligibility, Gains in Life Expectancy, and Social Policy" and in 2013 he received the *Mike McCracken Award for Economic Statistics* from the Canadian Economics Association "in recognition of both theoretical and applied contributions to the development of official economic statistics".

**JASON SUTHERLAND, PHD** is an associate professor at the University of British Columbia's Centre for Health Services and Policy Research (CHSPR) in the School of Population and Public Health, one of Canada's leading health policy research centers. He is a Scholar of the Michael Smith Foundation for Health Research, Canada's 2012-13 Harkness/CFHI Fellow in Health Care Policy and Practice, and a senior researcher at the Agency for Healthcare Research and Quality (AHRQ) in Maryland. Dr. Sutherland conducts research on health system performance, studies efficiency and effectiveness of Canada's health care spending, and evaluates patient-reported outcomes (PROs) for elective surgical care in Canada. Dr. Sutherland's research interests include health system performance, financial incentives, risk adjustment and variations in utilization and spending.

**KAREN TU, MD** is a family physician at Toronto Western Hospital, Senior Scientist at Institute for Clinical Evaluative Sciences (ICES) and Associate Professor and Research Scholar in the Department of Family and Community Medicine at the University of Toronto. She is experienced in data collection from primary care physician offices and data linkage to administrative databases and has extensive experience in health services research centered on the identification and management of hypertension and validation of administrative database algorithms to identify patients with a variety of chronic diseases. She has established EMERALD the Electronic Medical Record Administrative data Linked Database at ICES and current work centers around turning electronic medical record data into a researchable format.

**NATALIE WARRICK, MSC** is a Research Associate with the Balance of Care Research and Evaluation Group and PhD student at the Institute of Health Policy, Management and Evaluation, Dalla Lana School of Public Health, University of Toronto. She holds a Master's in Gerontology from the University of Southern California, and dual Bachelor's degrees in Anthropology and Psychology from the University of California at Berkeley. Ms. Warrick has previously worked at the Alzheimer Society of Toronto where she led the innovative Caregiver Framework for Seniors Program. This program provides self-directed respite supports to informal caregivers and engages community partners to heighten the profile of the crucial need for supports across the continuum of health and social care. Ms. Warrick is a project management specialist and leading expert in the analysis of home and community care survey and administrative data. She has applied her expertise on issues such as: multi-sector community support service needs of seniors, housing options for people living with dementia, and pedagogy for students in health professions.

Ms. Warrick’s published work in Healthcare Quarterly is helping to shape policy directions in home and community care as featured in the recent “Bringing Care Home Report” to Ministry of Health and Long-Term Care. Awards she has received include the Alzheimer Society Research Program Award and the Michael Decter Scholarship for Health Leadership and Policy studies. Ms. Warrick’s dissertation research is focused on the economic security for informal caregivers and the long-term health consequences of their employment-related wage loss.



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