

What is a Defendable Estimate of Dementia Prevalence and Monetary Costs?

**Presentation at the 30th International
Conference of Alzheimer's Disease
International, Perth Australia**

Friday, April 17, 2015

4:00PM – 5:30PM

River View Room 7

**Mimi Lowi-Young, M.H.A., Dip Bus. Admin., FACHE, FCCHL
Chief Executive Officer, Alzheimer Society of Canada**

Objectives of Presentation

- Why defensible estimates of dementia prevalence and costs?
- How does one reconcile major differences in prevalence of dementia now to 2031 across studies?
- What costs and outcomes of prevention, treatment, care and support should be included in projections to 2031?
- What are the 'preferred' 'dependable' single estimates for Canada that the Alzheimer Society of Canada should report?
- How should defensible estimates for provinces be produced?
- What knowledge gaps require future research?



Why defensible estimates of dementia prevalence?

Real World of Dementia

(collection, coding)

Data

*(processing, interpretation,
presentation)*

Information

(politics, commitment)

Action



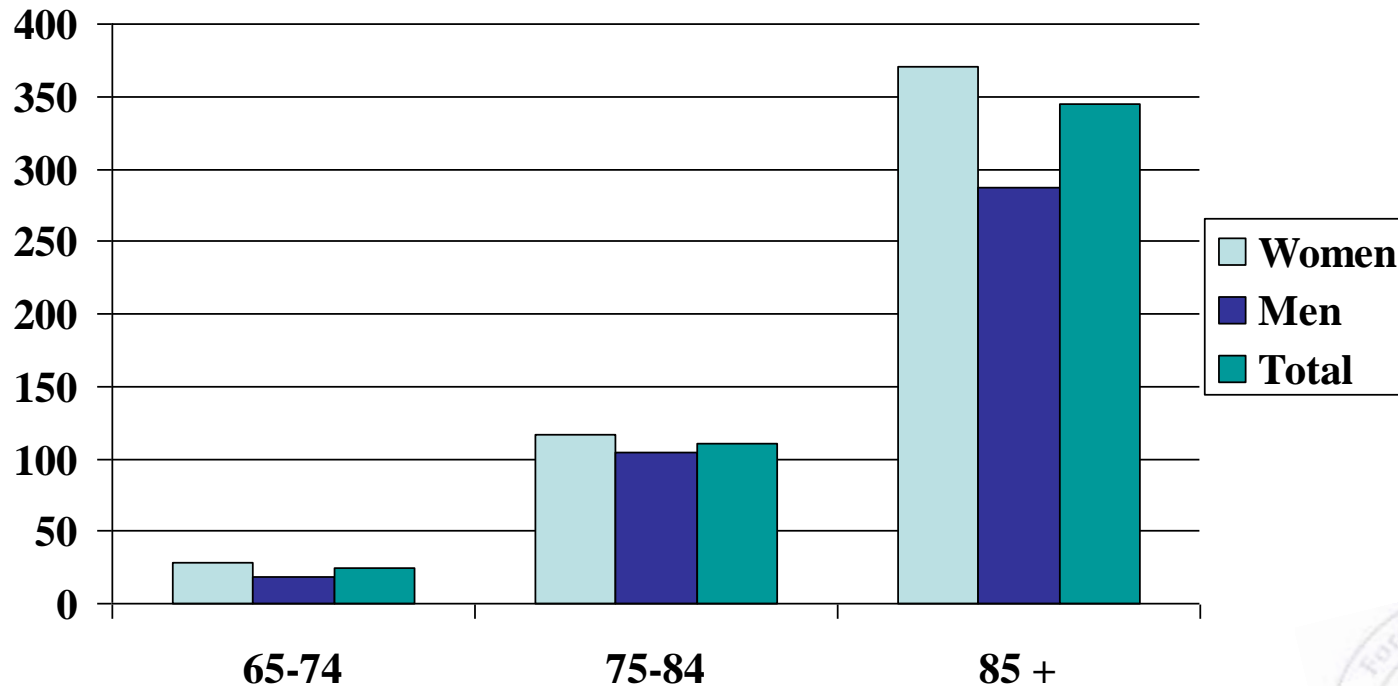
Why Defendable Estimate of Dementia Prevalence and Monetary Costs?

1. Support public policy and advocacy initiatives with governments
2. Improve work plans, budgets and projections
 - user friendly (e.g. single number not a range of numbers inform service planning at all levels)
 - robust so all sectors can use them with confidence
3. Increase public awareness about:
 - severity experienced by those living with dementia
 - costs of care
 - loss of income
 - availability and burden on family caregivers
 - other challenges



Prevalence of Dementia Canada 1991-92

Rate per 1,000

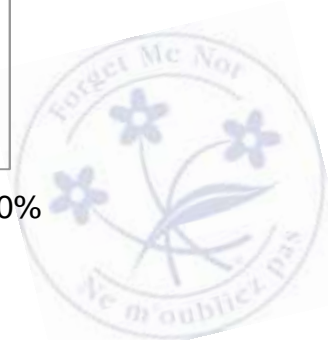
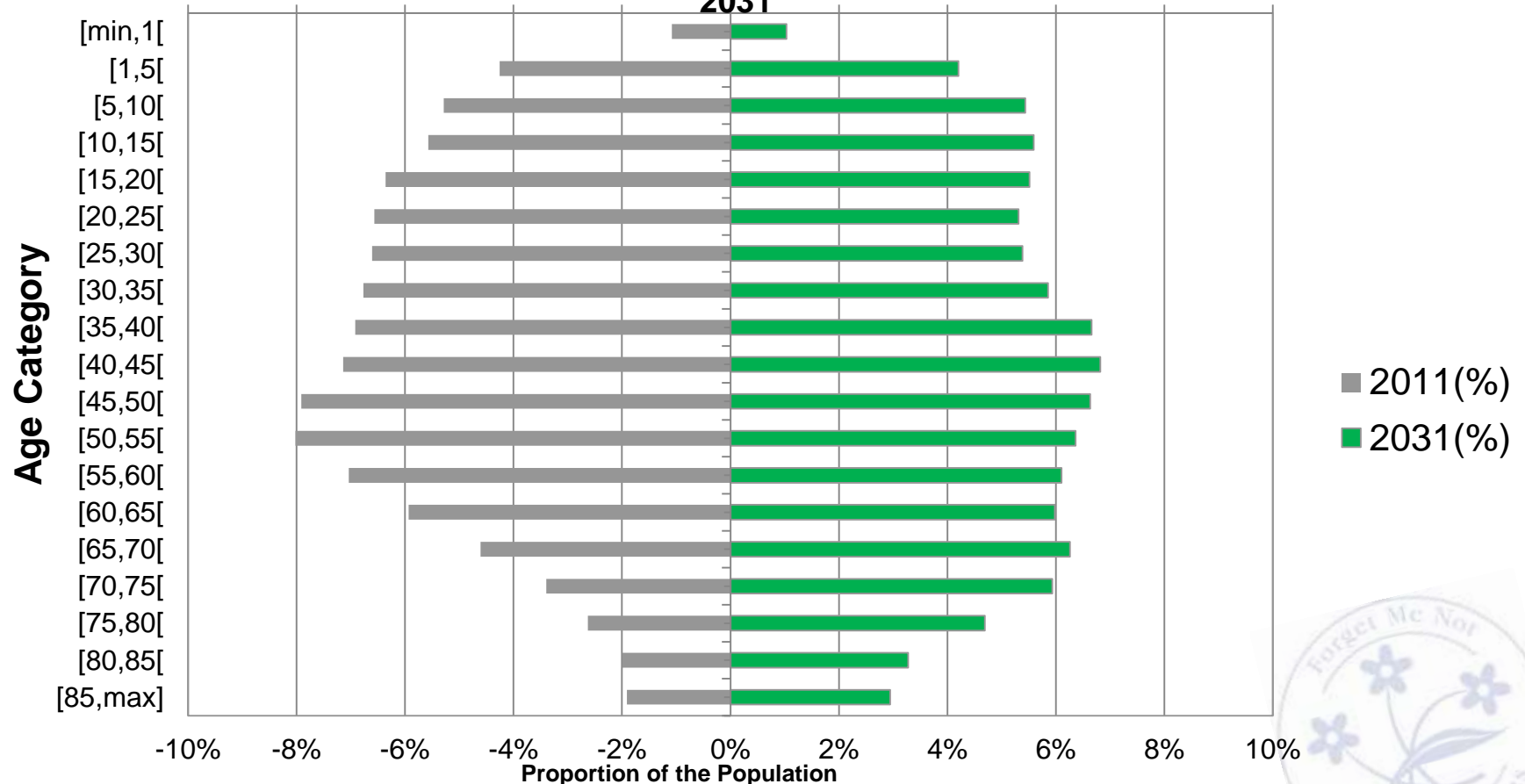


Source: *Can Med Assoc J* 1994;150:899-913

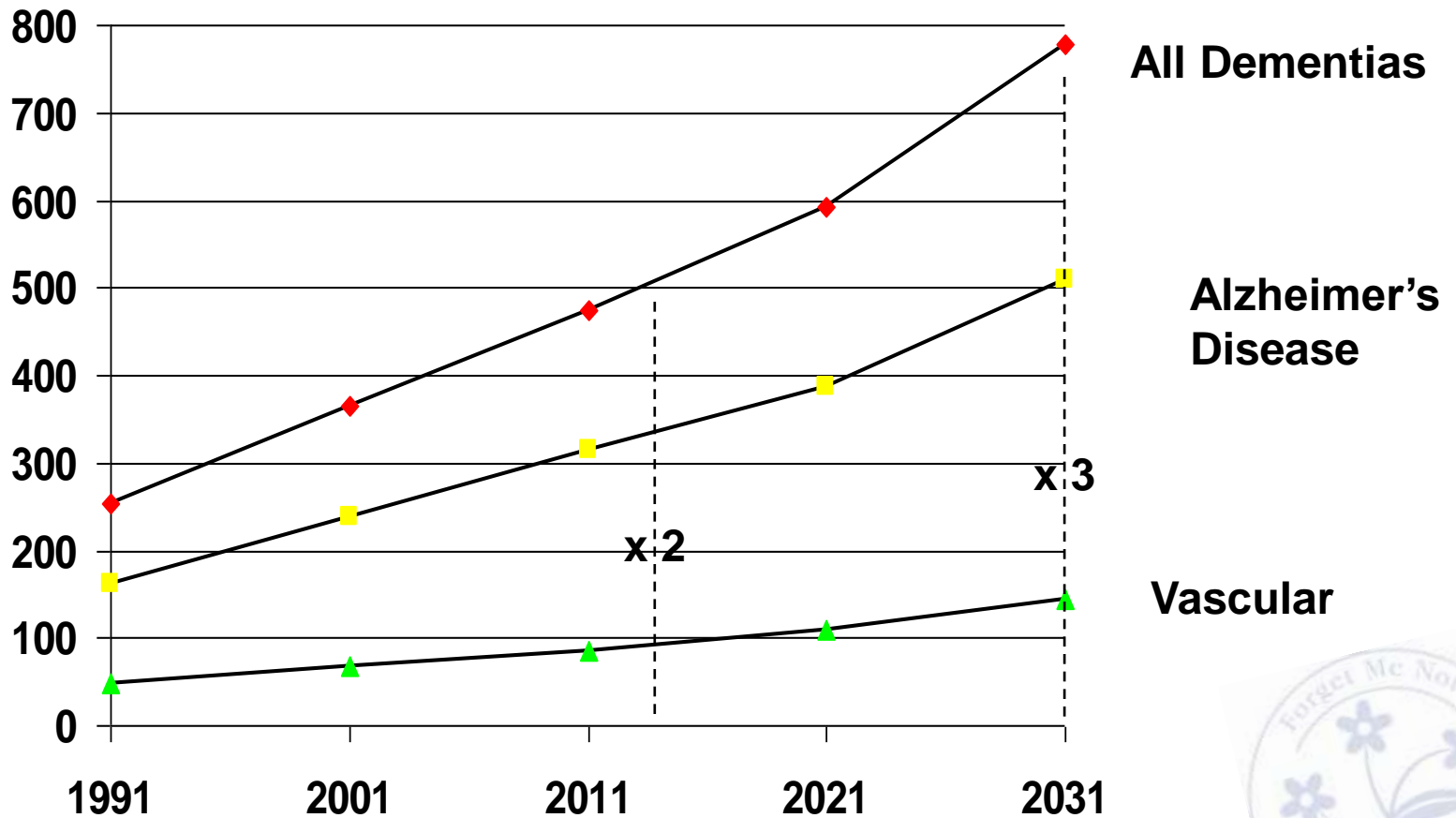


CONTEXT – By 2031, Canada's population is projected to grow to ~40 million and to see a shift in age structure

Projected Proportion of the Canadian Population by Age Category, 2011 and 2031



Projected Prevalence of Dementia (x 1,000) Canada, 1991 - 2031



Source: *CMAJ* 1994; 150: 899-913



Canada's most Authoritative and Reliable Estimates of Dementia Prevalence: the Canadian Study of Health and Aging 1991-2001

- Interviews and questionnaires with 9,008 people 65 years and over living in community and in long term care facilities.
- Clinical, neurological and neuropsychological examinations (2,914 of people with low cognitive scores and random sample with "normal" scores).
- Physical measurements of mobility and blood pressure.
- Laboratory tests were undertaken, and blood samples or genetic and other analyses.
- Abstracted information from death certificates and provincial health care utilization records for the study period.

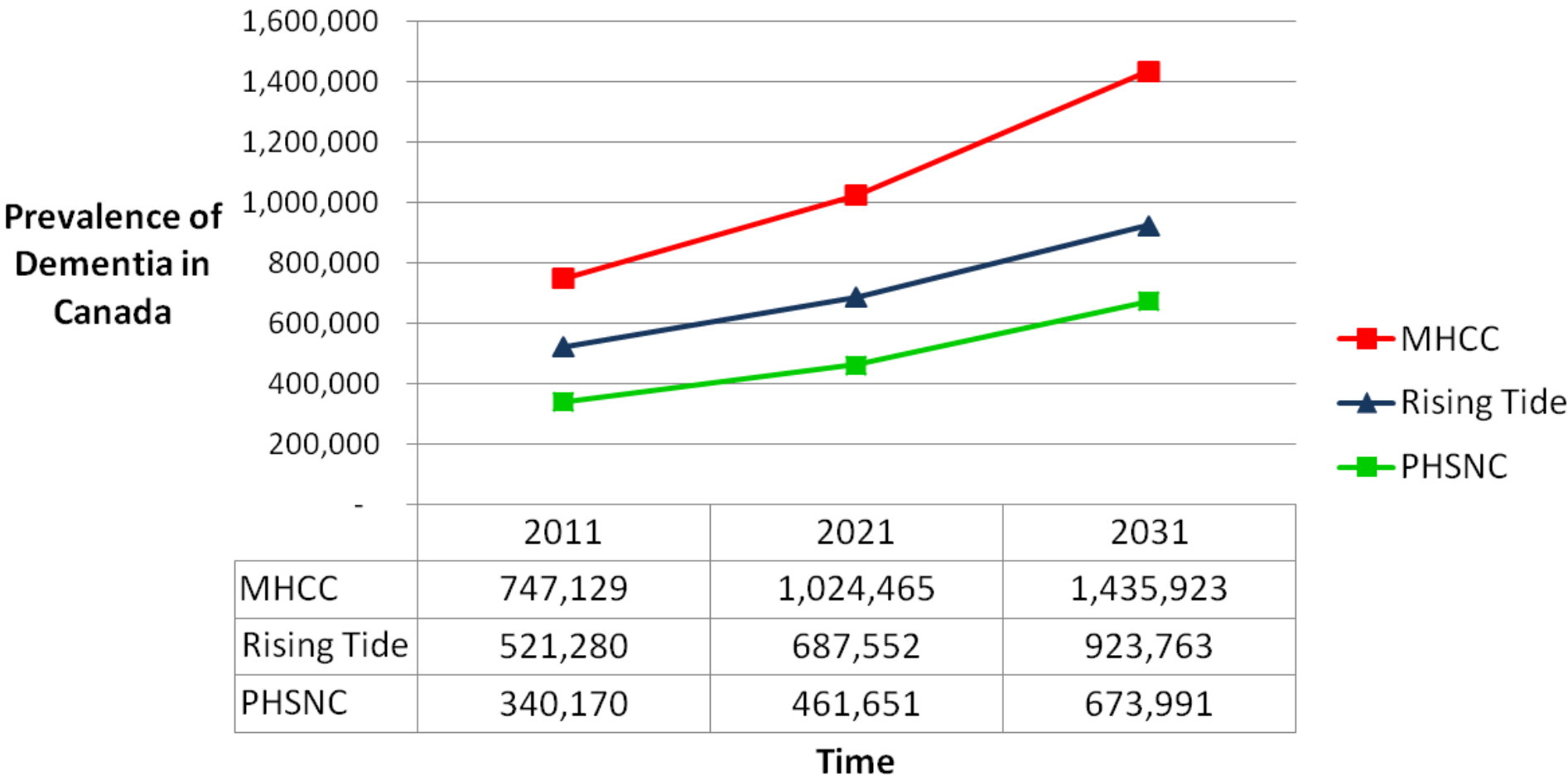


Three Recent Major Reports on Present and Future Dementia Prevalence and Monetary Costs

- Mental Health Commission of Canada, 2012 (Government of Canada)
- Rising Tide, 2010 (Alzheimer Society of Canada)
- National Population Health Study of Neurological Conditions, 2014 (Government of Canada)



Existence of Varied Prevalence Estimates Leads to Confusion and Impacts Credibility of Sources



MHCC = Mental Health Commission of Canada, 2012

Rising Tide = Rising Tide: Impact of Dementia on Canadian Society, 2010

PHSNC = National Population Health Study of Neurological Conditions, 2014

Future Study: Canadian Longitudinal Study of Aging but incidence data



Issues in Estimating Dementia Prevalence

- Varied prevalence estimates lead to confusion and impacts credibility of agencies providing estimates
- Two important determinants of differences in estimates of dementia prevalence are:
 - Decisions on what *level of severity* of dementia to include, that is, should mild cognitive impairment be included
 - different *data sources* have strengths and limitations



What level of dementia severity should be used in prevalence estimates?

- Canadian Study of Health and Aging
 - 8% of persons over 65 years of age had “definite or probable” dementia,
 - but another 8% had “mild cognitive impairment”
- adding people with mild cognitive impairment can *double* estimate of “dementia” in population



Inclusion of People with Mild Cognitive Impairment in three Reports

Report	Severity of Dementia
Mental Health Commission of Canada, 2012	Included people with dementia and people with mild cognitive impairment
Rising Tide, 2010	Did not include people with mild cognitive impairment
National Population Health Study of Neurological Conditions, 2014	Did not include people with mild cognitive impairment



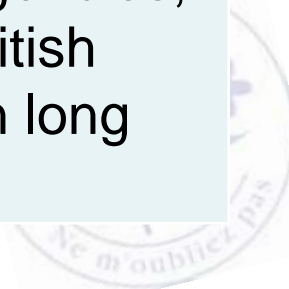
Source of Data and Dementia Prevalence

- Studies show that community surveys find *twice* as many cases of dementia than health administrative data



Data Source and Prevalence of Dementia

Report	Sources of Data
Mental Health Commission of Canada, 2012	Health services data, access and supply, utilization, costs (Province of Manitoba)
Rising Tide, 2010	National survey (Canadian Study of Health and Aging) and surveys from other countries (EURODEM)
National Population Health Study of Neurological Conditions, 2014	Health services data, access and supply, utilization, costs. Data from other agencies, social care, housing (Province of British Columbia including MDS InterRAI in long term home and residential care).



Annual Estimated Direct Costs of Dementia in 2031 in Three Reports

Report	In \$Millions
Mental Health Commission of Canada	\$92,863
Rising Tide	\$55,351
National Population Health Study of Neurological Conditions	\$16,000?

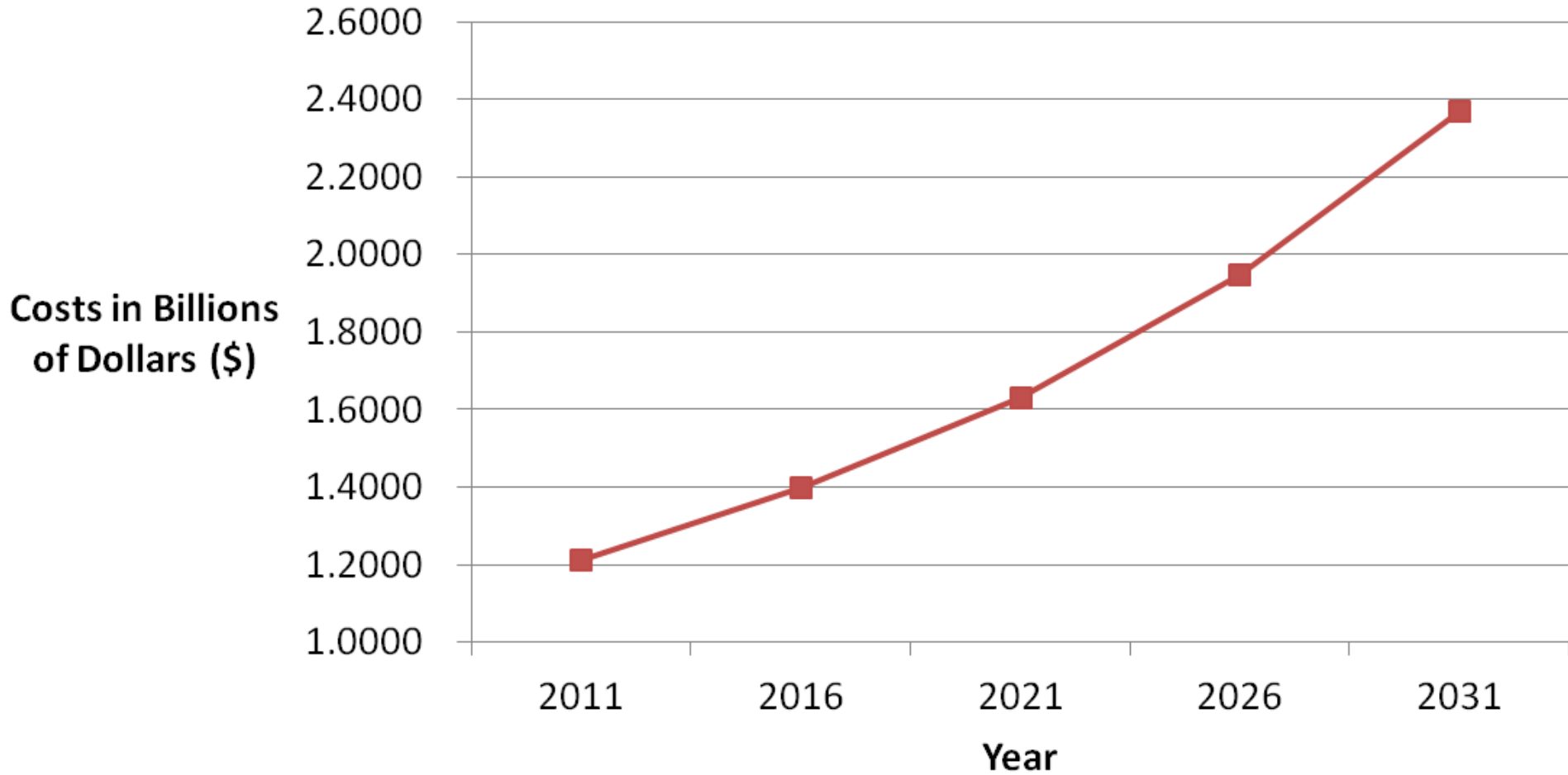


Issues in Estimating Dementia Monetary Costs

- Costs from societal perspective preferred
- Cost estimates are sensitive to:
 - Inclusion of different types of housing
 - number of persons with dementia within each housing type
 - Length of time in each stage of severity of dementia

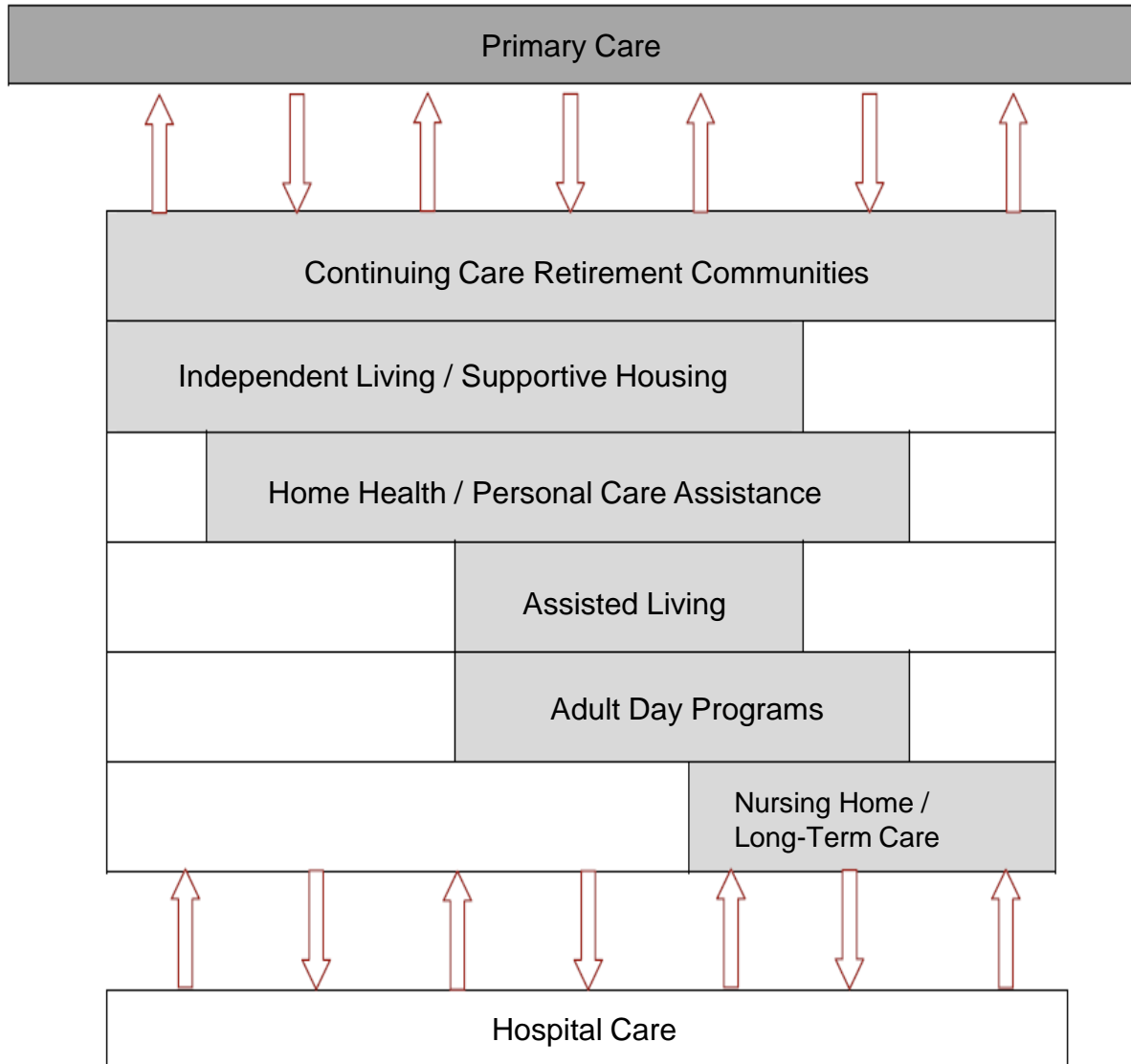


Total out-of-pocket costs to caregivers of individuals with Alzheimer's disease and other dementias



Independent Older Adult

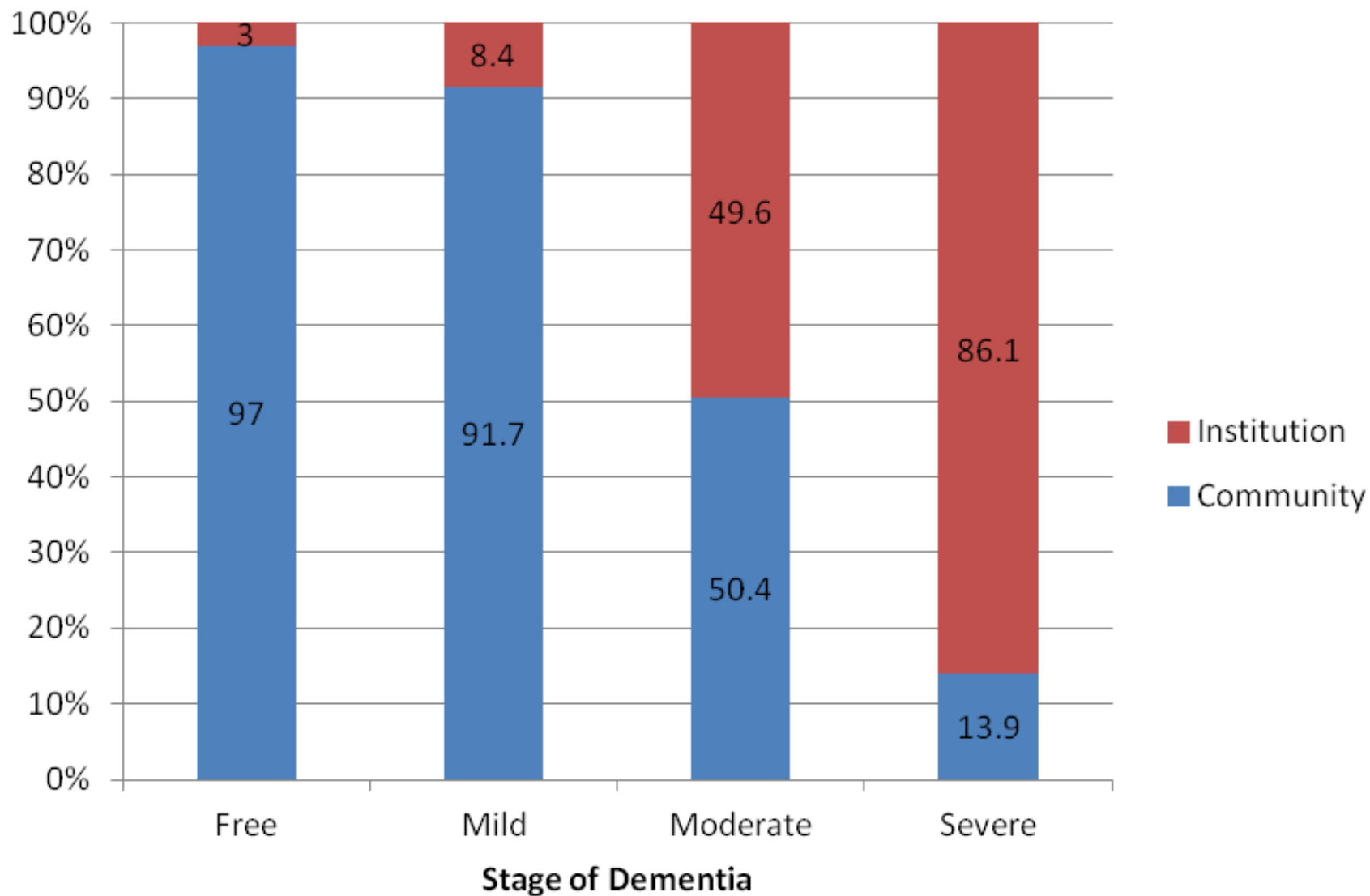
Dependent Older Adult



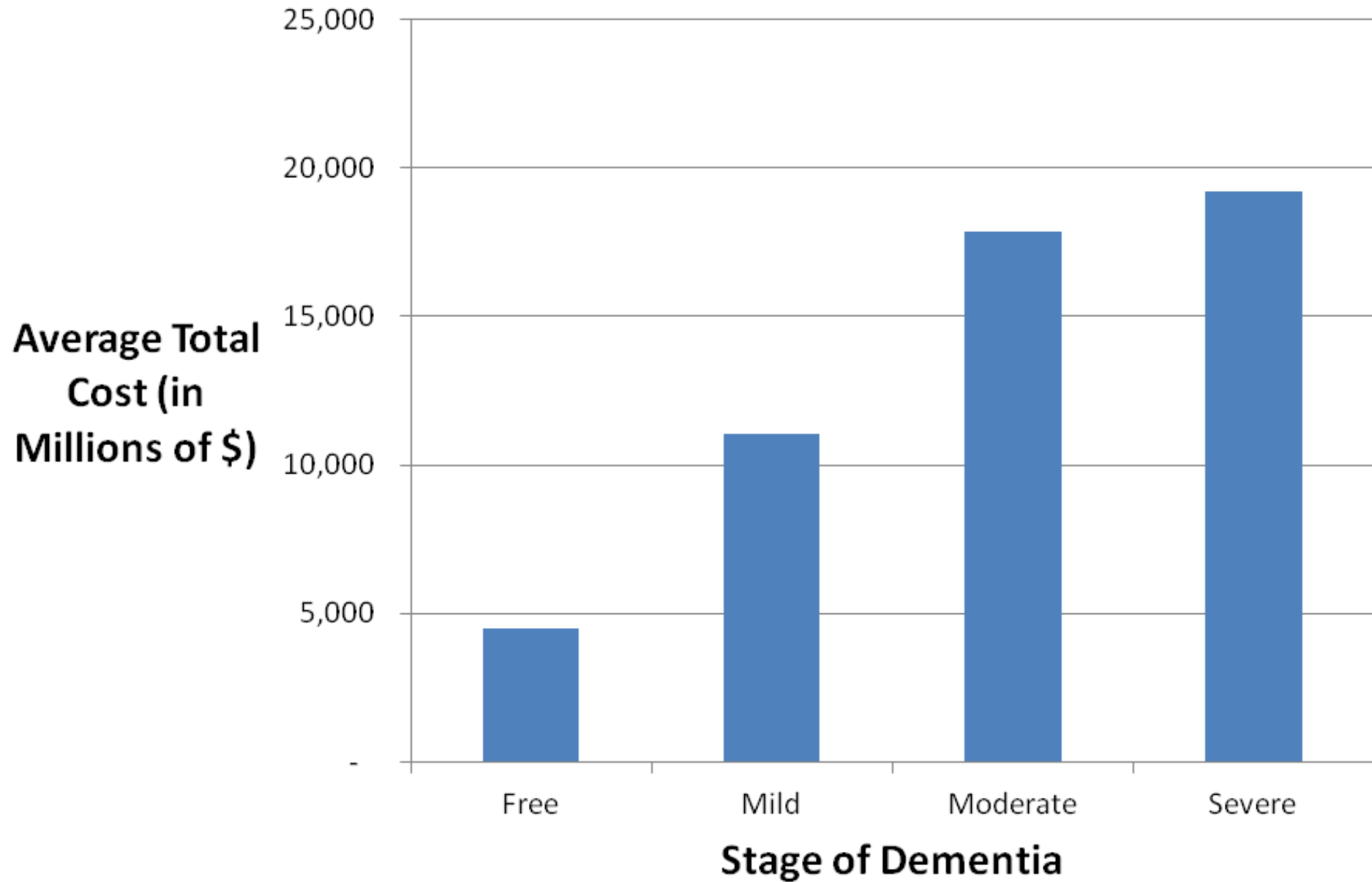
Continuum of Care and Services for Seniors and those requiring Continuing Care



Percentage of Individuals with Dementia in Community vs. Institution

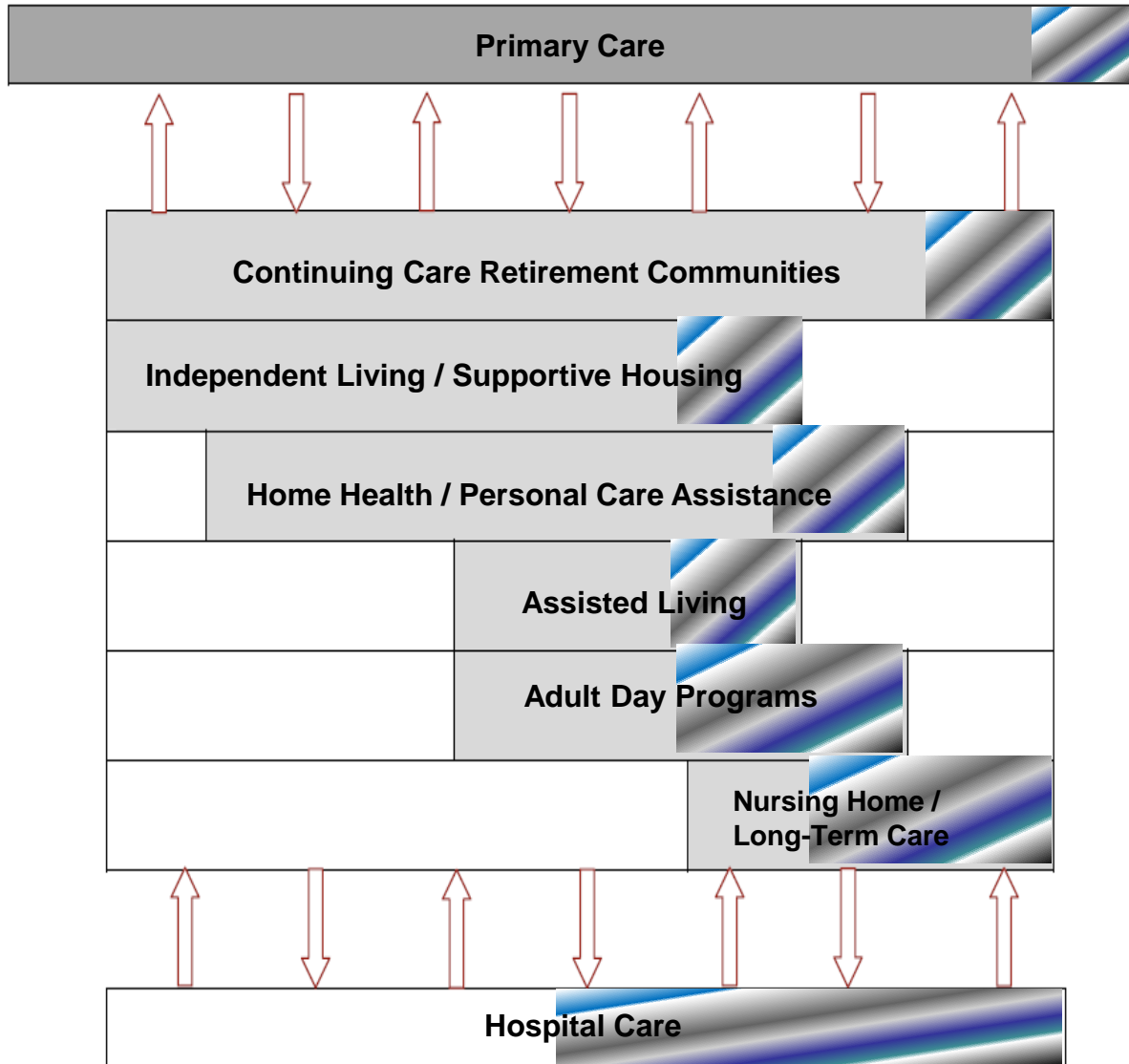


Cost of Dementia by Stage of Severity



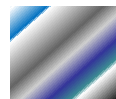
Independent Older Adult

Dependent Older Adult



Continuum of Care and Services for Seniors and those requiring Continuing Care: Estimated % with Cognitive Impairment

Legend

 = Estimated % of persons with cognitive impairment

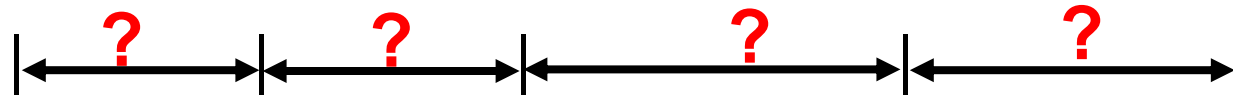


Data Required on Length of Time in Stages of Dementia

Stages of Dementia

Free Mild Moderate Severe Death

**Average
Time**



**Total
Average
Time**





The Canadian Longitudinal Study on Aging (CLSA)

- A key strategic initiative of the Canadian Institutes of Health Research (CIHR)
- More than 160 researchers - 26 institutions
- Follow 50,000 Canadians for 20 years
- Multidisciplinary - biology, genetics, medicine, psychology, sociology, demography, economics, epidemiology, nursing, nutrition, health services, biostatistics, population health



Next Steps: Workshop of Researchers and Policy Makers

- Members of Canadian and international research teams
- Policy makers from governments and the Alzheimer Society
- Use Workshop to:
 - Produce single estimate in Canada to be used by the Alzheimer Society of Canada
 - Advise provinces and territories of Canada on how to derive estimates using national estimates
 - Identify priorities for future research



Workshop Process



Summary of Presentation

- Alzheimer Society requires defensible estimates of dementia prevalence and costs
- Must acknowledge unavoidable uncertainty associated with estimating both prevalence and costs of dementia
- Workshop “process” will be used to create the “message” about dementia prevalence and costs for consumption by media, public and policy makers
- Workshop “process” also will identify knowledge gaps for future research priorities



Société Alzheimer Society

