



1:30pm – 2:15pm

The dementia challenge: Facing the rising tide

*Panel Organizer: Eleanor Fast
Canadian Academy of Health Sciences*



Canadian Academy of Health Sciences
Académie canadienne des sciences de la santé

CAHS Expert Panel for the Assessment of Evidence and Best Practices for the Development of a Canadian Dementia Strategy

Howard Bergman MD, FCFP, FRCPC, FCAHS; Panel Chair

Chair, Department of Family Medicine,
Professor of Family Medicine, Medicine and Oncology, McGill University

Carrie McAiney, PhD; Panel Member

Schlegel Research Chair in Dementia, Schlegel-UW Research Institute for Aging,
Associate Professor, School of Public Health and Health Systems, University of Waterloo

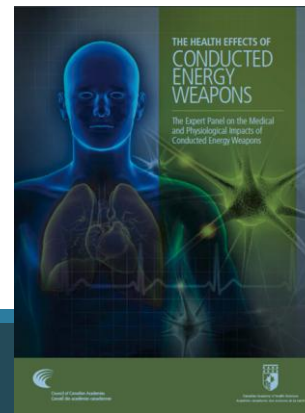
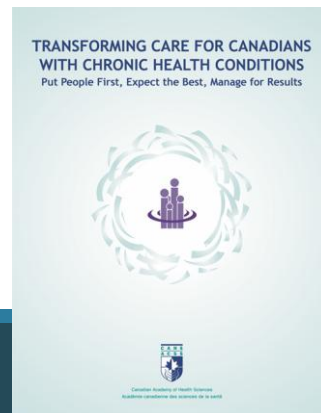
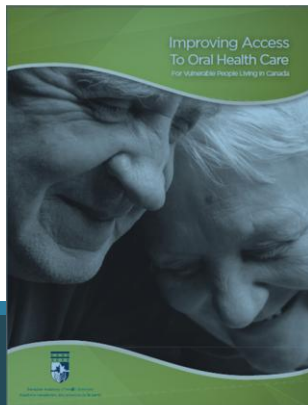
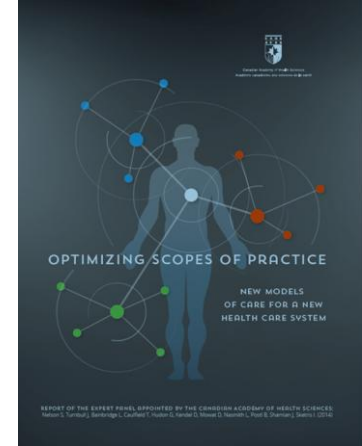
Isabelle Vedel, MD, PhD ; Panel Member

Assistant Professor, Department of Family Medicine, McGill University



Canadian Academy of Health Sciences(CAHS) – Who we are

- 700 Canadian health scientists widely recognized for academic achievement, creativity and leadership
- A collaborative body producing scientifically validated evidence and unbiased, actionable, solutions to address major health challenges affecting Canadians.
- Fellows from all health disciplines serve as unpaid volunteers to enhance the health & best interests of all Canadians
- Reports available at: www.cahs-acss.ca





Dementia: Quick facts

- Dementia is not a normal or inevitable part of aging
- 1 in 8 baby boomers will likely develop dementia
- One-third of seniors who die have been diagnosed with dementia.
- More than 90% have at least one other chronic condition and close to 20% have five other chronic conditions.
- Total health care system & out-of-pocket costs: \$16.6 billion by 2031
- Life-style factors may have the potential to delay, if not prevent, onset



Act of Parliament: 2017

National Strategy for Alzheimer's Disease and Other Dementias Act

- Develop and implement a comprehensive national strategy to address all aspects of Alzheimer's disease and other form of dementia

Why a national strategy?

- More people will be living with dementia
- Increased availability of biomarkers for pre-symptomatic detection of Alzheimer's disease and disease modifying medications
- Need to ensure the sustainability of the health and social care system

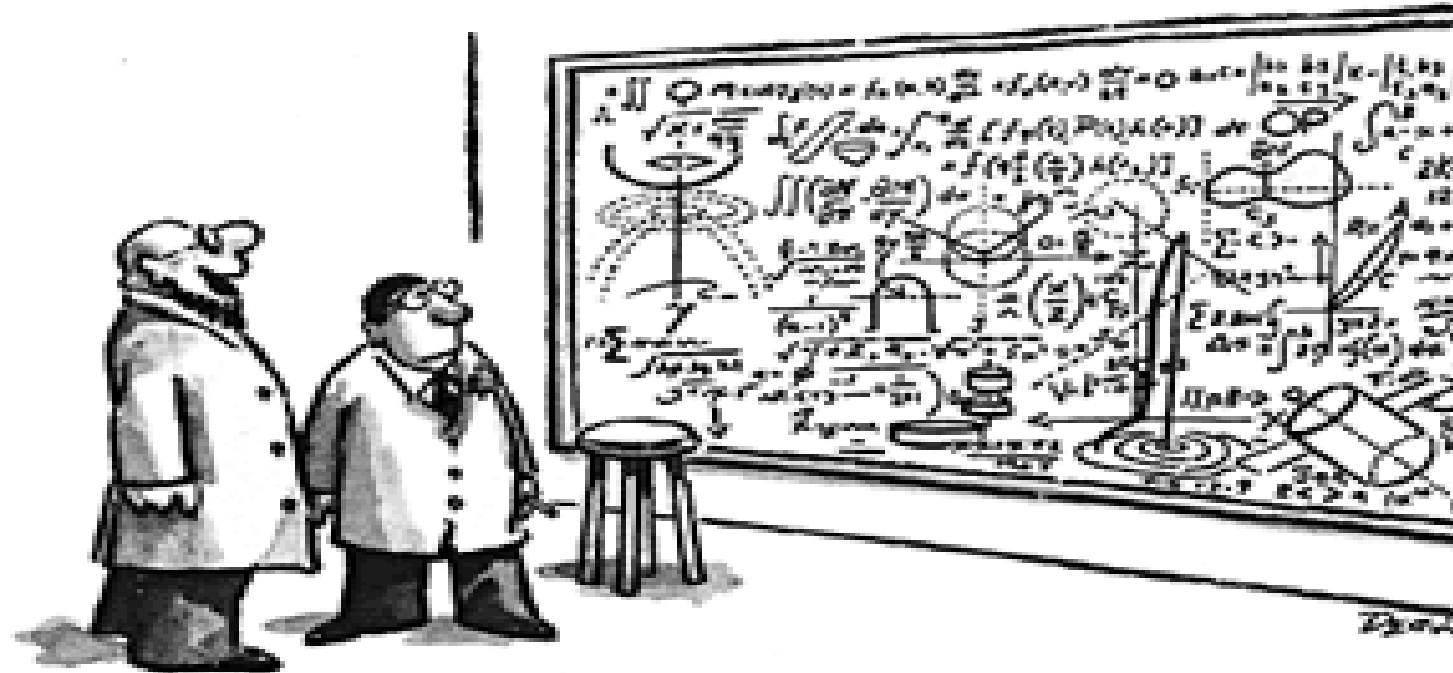


Charge to CAHS

Minister of Health of Canada, through the Public Health Agency of Canada (PHAC), charged the CAHS to provide:

- An evidence-informed and authoritative assessment on the state of knowledge and practice
 - Summarize strength/ state of the evidence and emerging best practices
 - Inform, not write the national plan
- A «rapid assessment» aligned with the vision of CAHS
 - Informed actionable solutions that improve the health of Canadians.

**A body of evidence simultaneously
overabundant and insufficient
8 month deadline**



"Hey, no problem!"



Composition of the Panel

To address the charge, the CAHS assembled a multidisciplinary, multi-sectoral panel of six experts with a range of expertise, experience, and demonstrated leadership in this domain.

Chair: **Howard Bergman**, MD, FCFP, FRCPC, FCAHS. Chair of the Department of Family Medicine, Professor of Family Medicine, Medicine and Oncology, McGill University

David Hogan, MD, FRCPC, Academic Lead of the Brenda Strafford Centre on Aging, O'Brien Institute for Public Health, Cumming School of Medicine, University of Calgary

Janice Keefe, PhD, Professor and Chair, Department of Family Studies and Gerontology and Director, Nova Scotia Centre on Aging, Mount Saint Vincent University

Carrie McAiney, PhD, Schlegel Research Chair in Dementia, Schlegel-UW Research Institute for Aging, Associate Professor, School of Public Health and Health Systems, University of Waterloo

Debra Morgan, PhD, RN, FCAHS, Professor, College of Medicine Chair in Rural Health Delivery, Canadian Centre for Health & Safety in Agriculture, University of Saskatchewan

Isabelle Vedel, MD, PhD, Assistant Professor, Department of Family Medicine, McGill University

Project Director: **Sonya Kupka**, MAdEd, RD, SJK Consulting





Approach

1. Highlight the **challenges** from the perspectives of people living with dementia and their caregivers, and the health and social care system
2. Summarize **public-policy responses** as expressed in dementia strategies and relevant legislation
3. Identify **evidence informed and emerging best practices** that are relevant to the Canadian context, emphasizing how they can and must be translated in a coherent and practical way into the existing health and social care system
4. Highlight **key findings**.



Key Considerations

Build on the rich Canadian experience

- Provincial AD Plans since the late 1990s
- Four Canadian Dementia Consensus Conferences since 1989
- Research and emerging best practices

Address dementia as a societal, health and social issue emphasizing the complex combination of health and social needs of persons living with dementia and their caregivers

- Recognizing the rights of people living with dementia and accommodating their needs is fundamental
- Education on maintaining brain health and preventing dementia empowers people and societies to take action
- A person-centered approach to care is based on knowledge of the person with dementia and their caregiver, a commitment to partner with them, and an understanding that needs will evolve



Key Considerations

Recognize the centrality of engaging persons living with dementia and their caregivers in a meaningful and respectful manner

- With timely diagnosis and mobilization of the right amount and type of health and social supports, people diagnosed with dementia can actively participate in making decisions about their lives and lead personally meaningful lives
- The needs of caregivers are not identical to those of care recipients and need to be specifically addressed
- There is a diversity of persons living with dementia and their caregivers

Ensure an adequately trained and supported dementia workforce is available to deal with current and anticipated demand

- Address both training needs and organizational supports for quality team-based care by an appropriate mix of health care providers



Key Considerations

Assure an equitable balance in research investment across biomedical, clinical, health services, and social, cultural, environmental, and population health and between creating and translating knowledge

- Canada has specific research needs and there are opportunities to capitalize on our unique advantages

Create, seek out and utilize evidence and best practices to implement the strategy in a coherent and practical way

- In Canada, assessment, management and treatment are anchored in team-based primary care and integrated with other components of the health and social care system
- Flexibility in implementation allows local adaptation



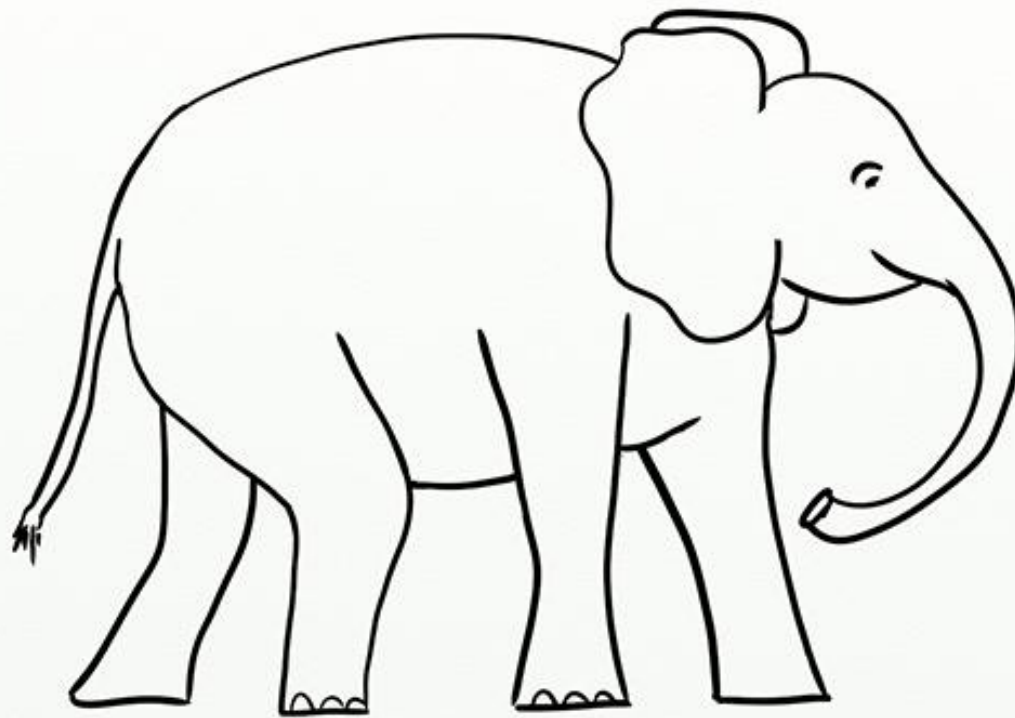
Engaging People Living with Dementia



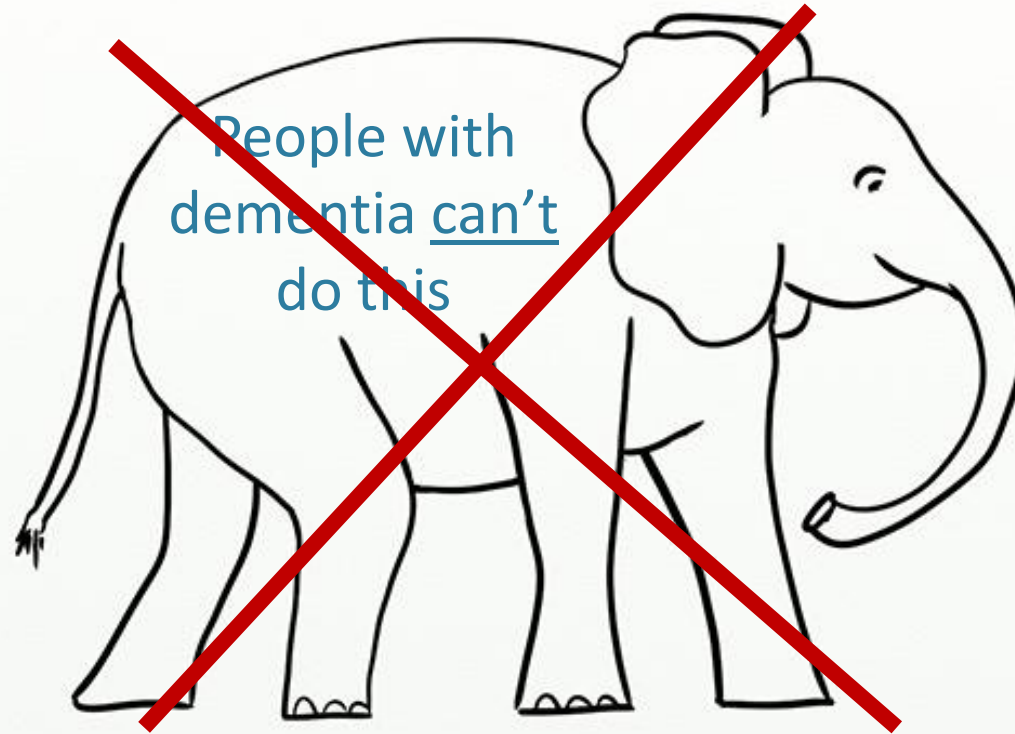
What do we mean by engagement?

- Care decisions
- Planning for the future
- Daily lives & activities
- Advocacy
- Programs & services (design, evaluation)
- Research – as partners vs. participants

Engagement must be genuine and meaningful









Research on Engaging People Living with Dementia

- People living with dementia want to be engaged
- Perspectives of “proxies” are often different than those of persons living with dementia; Examples:
 - Whether those with dementia want to be involved
 - How important certain values are when making decisions (e.g., autonomy, burden, safety)



What's Needed?

- Understand how best to engage people living with dementia
- Understand the impacts of engagement – on those with dementia and others
- Ensure that diversity is considered



The Challenge of Implementation

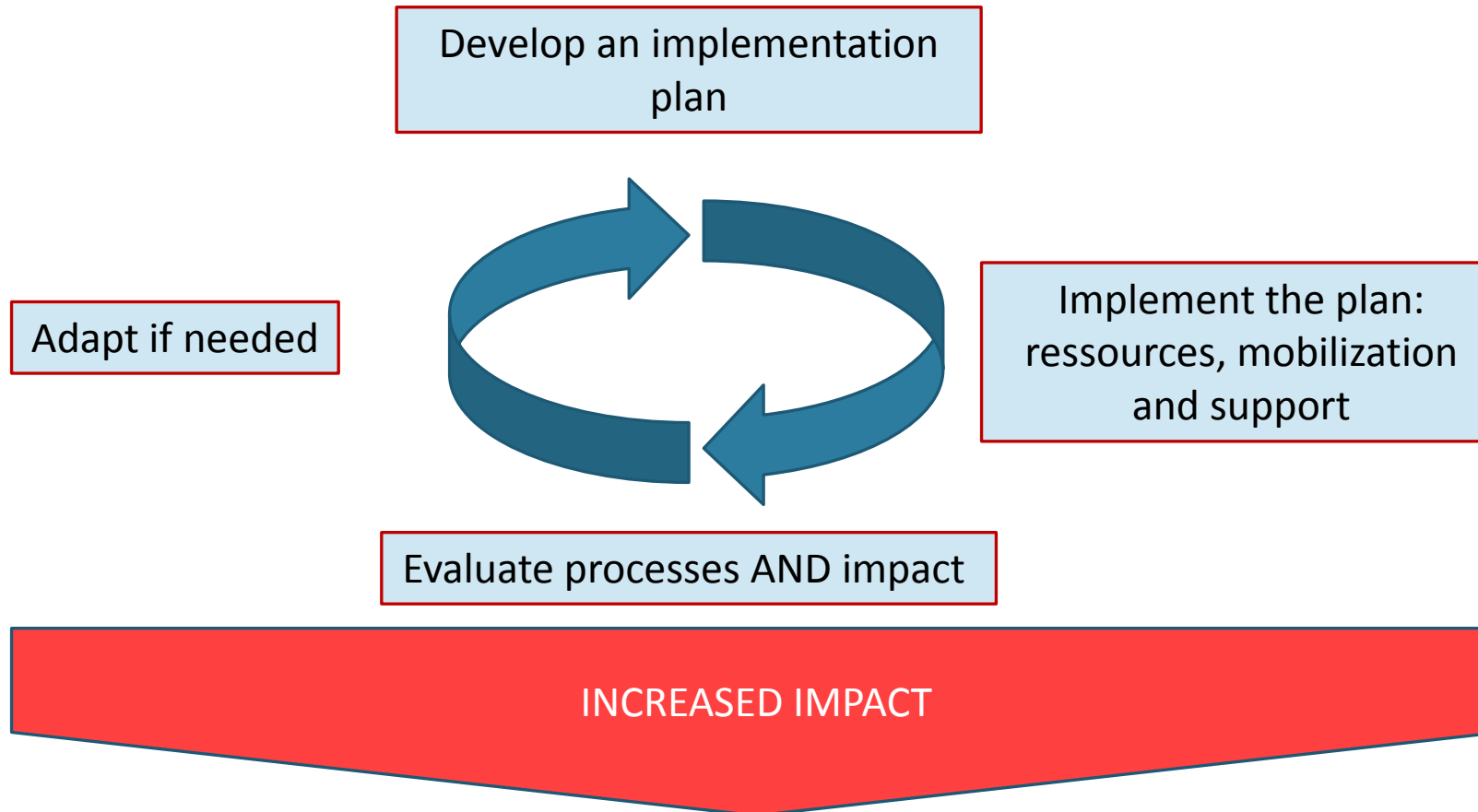


Why an implementation plan is key ?

- Change is challenging
 - Canadian healthcare systems and organizations have limited capacities to adapt, innovate and improve
 - Many innovations fail to successfully transition from adoption to sustained implementation
- 32 national and sub-national Alzheimer strategies have been developed
 - Defined implementation plan (precise objectives and metrics) in very few of them
 - No evaluation, except UK and France, but mainly on processes, not on impact
- **A sound implementation plan combined with an evaluation of impact is key to achieving the goals of dementia strategies**



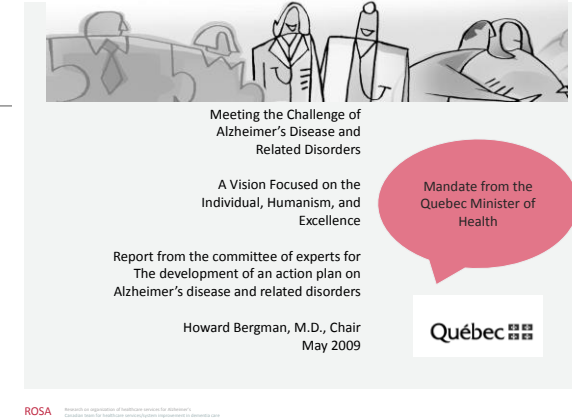
Virtuous cycle: implementation and evaluation





Implementation and evaluation: example from QC

- Ministerial decision
- Incremental Implementation with evaluation
 - First: in 19 projects representing 40 Family Medicine Groups (2012-2016)
 - \$250,000 per project
 - Support: Project managers, guidelines, training
 - Evaluation of processes (key barriers and facilitators) and impact (quality of care)
 - Then: adaptation and scaling up to the whole province
 - Evaluation of processes (sustainability) and impact (quality of care, use of services)





Report Launch

- Report will be launched in January 2019 and posted at <https://www.cahs-acss.ca/improving-the-quality-of-life-and-care-of-persons-living-with-dementia-and-their-caregivers/>
- Sign up to receive a copy by email when it is launched
- Thank you to PHAC for engaging with CAHS on this important issue



Questions



CAHS Dementia Assessment

- Out of scope
 - Not charged to write the plan
 - Elements outside of health/social services
 - Stakeholder consultation
 - Federal/provincial jurisdiction



Methodology

A methodology scientifically reasonable and proportionate response to the challenge posed

- An extensive highly iterative process
 - a blend of evidence, emerging ideas and consensus.
 - Examined Canadian and international reviews; commissioned a review of AD policies in OECD countries; commissioned reports; in some cases examined source research
 - provincial strategies provided direction
- CAHS Expert Panel members took responsibility for:
 - provided initial orientation and reviewed evidence and identifying best practices for assigned areas that aligned with their expertise
 - Actively engaged in writing sections of the report



Commissioned Papers

The CAHS Expert Panel requested short papers from experts and researchers to better understand the following areas:

- Rural dementia care
- Ethnic minorities and recent immigrants
- Young-onset dementia
- Indigenous populations in Canada
- Sexual minorities
- Adults with intellectual/developmental disabilities
- Technology for dementia
- International review of Alzheimer's disease policies in OECD countries

These papers reflect the opinions of their authors. They were read by and informed the work of the Expert Panel. They were not, though, endorsed by Expert Panel or CAHS. They will be available on the CAHS website as an addendum to the assessment report.



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