A Global Response to the Global Challenge of Dementia

Yves Joanette, Chair
Raj Long, Vice-Chair

OECD, Paris, 2017
DEMENTIA

Is NOT a specific disease.

Is a GROUP OF SYMPTOMS affecting intellectual and social abilities severely enough to interfere with daily functioning.

Alzheimer's disease is the most common cause of a progressive dementia.

Memory loss generally occurs in dementia, but memory loss alone does not imply you have dementia.

Source: Phipps, Alzheimer Association, 2014
Diseases Causing Dementia

- Alzheimer’s disease
- Vascular dementia
- Mixed
- Dementia with Lewy bodies
- Parkinson’s dementia
- Frontotemporal dementia
- Other

Source: Alzheimer Research UK, 2017
Increase in numbers of people with dementia worldwide (2010-2050), comparing original and updated estimates

- 2010: 36 million
- 2013: 44 million
- 2030: 66 million (Original) / 76 million (Updated)
- 2050: 115 million / 135 million

World Dementia Council
Leading the Global Action Against Dementia

Alzheimer's Disease International
The global voice on dementia

Policy Brief for Heads of Government
The Global Impact of Dementia 2013–2050
The World is Aging

Prevalence of Dementia

Approx. 6-8 %

Approx. 30-35 %

Source: United Nations Department of Economic and Social Affairs, Population Division, World Population Prospects, 2005

Source Alzheimer Society Canada, 2016
World population is aging.

Even more for the oldest.

Main risk factor for dementia: age.

Incidence increases with age.

The Longevity/Dementia Vicious Circle.
Numbers of people with dementia by world region (2015-2050)

North America: 11.74
Latin America & Caribbean: 18.78
Africa and the Middle East: 16.0
Europe Central and Eastern: 4.73
Asia (high income): 12.35
Asia (low and middle income): 63.16
World: 135.46

Courtesy of Martin Prince (2015)
Facing a ‘tidal wave’ of dementia, China is running out of time

Thirty years from now, China’s elderly population will vastly outnumber its younger citizens. In a country where assisted-living homes are scarce, and dementia is not widely understood, asks Nathan VanderKlippe, will people pay the price before the government does?
I can think of no other condition that has such a profound effect on loss of function, loss of independence, and the need for care. I can think of no other condition that places such a heavy burden on society, families, communities, and economies. I can think of no other condition where innovation, including breakthrough discoveries, is so badly needed.

G8 Dementia Summit, London, 2013

The Telegraph

Older people are more scared of dementia than cancer, poll finds

Two thirds of people over 50 are scared of developing dementia, while just one in 10 were frightened about getting cancer

Dr Margaret Chan
Director-General
World Health Organization
In Dec 2013, UK hosted a G8 Dementia Summit to bring together experts across the world to start a global conversation about solutions for dementia. The Summit resulted in a declaration that set out an international response to dementia with the aim of identifying a cure or a disease modifying therapy by 2025. France’s President Sarkozy had put Alzheimer as a national priority in 2008 and lead a European rally around collaborative research at the origin of JPND.
Post-G7 Summit World Dementia Council

- In February 2014, the UK Prime Minister appointed Dr Dennis Gillings as the World Dementia Envoy & established the World Dementia Council (WDC)
- WDC Members are from a wide range of experts from research, academia, industry, the NGO sector, people living with dementia & governments
G7 Summit Follow-up

- March 2015 – The First WHO Ministerial conference in March 2015 that allowed for a broad consensus
  - Establishment of a Global Dementia Observatory
  - Establishment of a working group to identify research priorities to face the global challenge of dementia

THE LANCET Neurology

Research priorities to reduce the global burden of dementia by 2025

Hiral Shah, MD, Prof Emiliano Albanese, MD, Cynthia Duggan, PhD, Igor Rudan, PhD, Prof Kenneth M Langa, MD, Maria C Carrillo, PhD, Kit Yee Chan, PhD, Yves Joanette, PhD, Prof Martin Prince, MD, Prof Martin Rossor, MD, Shekhar Saxena, MD, Heather M Snyder, PhD, Reisa Sperling, MD, Prof Mathew Varghese, MD[Psych], Huali Wang, MD, Marc Wortmann, Master of Law, Dr Tarun Dua, MD.
G7 Summit Follow-up

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  - Establishment of a Global Dementia Observatory
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- Spring 2016 – Vote by the Executive Committee of the World Health Assembly to consider a Global Action Plan
- Spring 2017 – Hopefully, adoption of a WHO Global Action Plan for Dementia
The Current World Dementia Council

- Has now become an independent entity
- Now truly addresses the global challenge
- Membership has been expanded and diversified
  (LMIC) UK membership has been expanded globally
Diseases Causing Dementia
A Very Complex Challenge

Prevent     Cure/Delay   Care

Sperling et al., Alzheimer’s & Dementia, 2011
Adapted from Jack et al., Lancet Neurol., 2010
Current Priorities of the Council

1. Favor integrated drug development
2. Advocate for innovative and global finance models
3. Encourage open science collaborative global research including big data
4. Stimulate adequate care for people living with dementia and their carers in high, middle and low-income countries
5. Facilitate the identification and the dissemination of risk reduction strategies

Integrating cross-cutting themes
- Women and dementia
- Awareness
- Stigma
- Inequalities
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Current Priorities of the Council

Prevention       Cure/Delay       Care
Actions of WDC do not duplicate those of its stakeholders (e.g. WHO, ADI, OECD, etc) but support/connect/synergize them.

Given the context, the goal is:

- To include and extend initiatives started in HIC (e.g., G8) to LMIC.
- To mobilize expertise and efforts to address specific needs of LMIC.
- To create a space of bilateral exchanges between actions in response to the challenge of dementia in HIC and LMIC.
- To strive towards the construction of a truly global space of collaboration addressing both specificity and the need for sharing.
Global Lead
Chris Llewellynn

- Design and promote a funding dashboard using existing data to show current funding across the spectrum of dementia-related activities and to highlight disparities and critical gaps
- Identify existing/innovative alternative funding models and approaches that could be applied to dementia, e.g. Cancer, HIV etc.
- Use the dashboard and data on funding models in order to reduce/eliminate funding disparities by influencing funder decisions
In March 2015, the WDC helped to shape the UK Govt-led work to establish the **Dementia Discovery Fund** – a ground breaking public/private venture capital fund which aims to finance pre-clinical research to find new drugs to treat dementia.

- The initial fund level is just over $100m & it aims to raise a further $100m during 2016
Integrated Drug Development

Global Lead
Raj Long
Deputy Director, Bill & Melinda Gates Foundation

- Identify and engage key payer groups for medicines/health technologies in Europe and globally, e.g. National Institute for Health Clinical Excellence (NICE) in the UK
- Develop a robust strategy for engaging payer groups, taking into account different models that exist (e.g. varying guidelines, expectations etc.)
- Identify strategic drivers to enable the development of a global plan for access to dementia treatments and to support adoption of the plan
Facilitate the global expansion of funding programmes such as the EU Joint Programme in Neurodegenerative Diseases

Develop a global statement promoting open science

Promote the use of big databases to public and private payers

Convene stakeholders to advocate for increased collaboration in dementia research and to address barriers

Influence Governments to invest in public intervention trials to demonstrate the benefits of risk reduction
Facilitate the global expansion of funding programmes such as the EU Joint Programme in Neurodegenerative Diseases (Montreal, October 2016)
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Research, Open Science and Big Data
• Introduce and disseminate a bold World Dementia Council statement around the importance of, and principles for, optimal dementia care
• Identify gaps in current knowledge around dementia care, including the areas with greatest potential for generating the most impact and benefits for people with living with dementia and their caregivers
GBHI is creating an international network of leaders in brain health
Influence global programmes focused on healthy ageing/brain health (e.g. Global Brain Health Institute – GBHI, Global Council on Brain Health, etc.), to ensure the inclusion of the perspectives and needs of Low and Middle Income Countries (LMICs).

Support LMICs to engage in Risk Reduction activities – e.g. by facilitating a risk reduction pilot project in Indonesia with support from the GBHI Fellows or Scholars Programmes.

Engage into pilot programs in LMIC
The Global Council on Brain Health (GCBH) is an independent collaborative of scientists, health professionals, scholars and policy experts from around the world working in areas of brain health related to human cognition. The GCBH focuses on brain health relating to peoples' ability to think and reason as they age, including aspects of memory, perception and judgment. The GCBH is convened by AARP with support from Age UK to offer the best possible advice about what older adults can do to maintain and improve their brain health. GCBH members come together to discuss specific lifestyle issue areas that may impact peoples' brain health as they age with the goal of providing evidence-based recommendations for people to consider incorporating into their lives.
Cross-Cutting Priorities

Towards a Global Response

• **Women and Dementia** – Ensure an adapted global response to the specific challenge of women in LMIC (Global Alliance on Women’s Brain Health)

• **Awareness, Stigma, Inequities** – Work with global organizations to enhance the consciousness about dementia in LMIC and diminish the stigma while supporting a human right approach for people living with dementia
“Ninchisho (Dementia) Supporter Caravan”
Supporter Training in Communities

National Caravan-Mate Coordinating Committee
Hiroko Sugawara

Join Gina and become a Dementia Friend.
It’s really easy to do. Simply attend a face-to-face Information Session or watch the video.

I’m a Dementia Friend

Become a Friend
Witchcraft and Dementia in Namibia

JUNE 6, 2016 / LEAVE A COMMENT

Witchcraft and Dementia in Namibia

Summary of Witchcraft and its Implications for the Elderly and People With Dementia

Would you not be afraid of being accused as a WITCH?

JUNE 7, 2016 / BERRIEJH
• WFSJ provides a support environment for 9000 journalists around the world
• Toolboxes can be prepared and disseminated to general journalists on specific topics
• WDC is in discussion with WFSJ to prepare a Dementia Toolbox that would help journalists from all continents
• Goal is to support journalists to enhance awareness of dementia and contribute to coverage of the May 2017 WHO vote on Global Action Plan
World Dementia Council

Member States

Funders
JPND
IADRFIC
WW-ADNI

WHO

NGOs
ADI
WFSJ

PLWD

Academia
GBHI

CEOi

Industry
World Dementia Council

Diagram showing various organizations and entities, including:

- OECD
- WHO
- JPND
- IADRF
- WW-ADNI
- GBHI
- ADI
- GCBH
- WFSJ
- CEOi

The diagram is centered on the term "PLWD."
World Dementia Council
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