


**World Dementia
Council** Leading the Global Action
Against Dementia

Global Action Against Dementia: Finding a Path Forward and the World Dementia Council

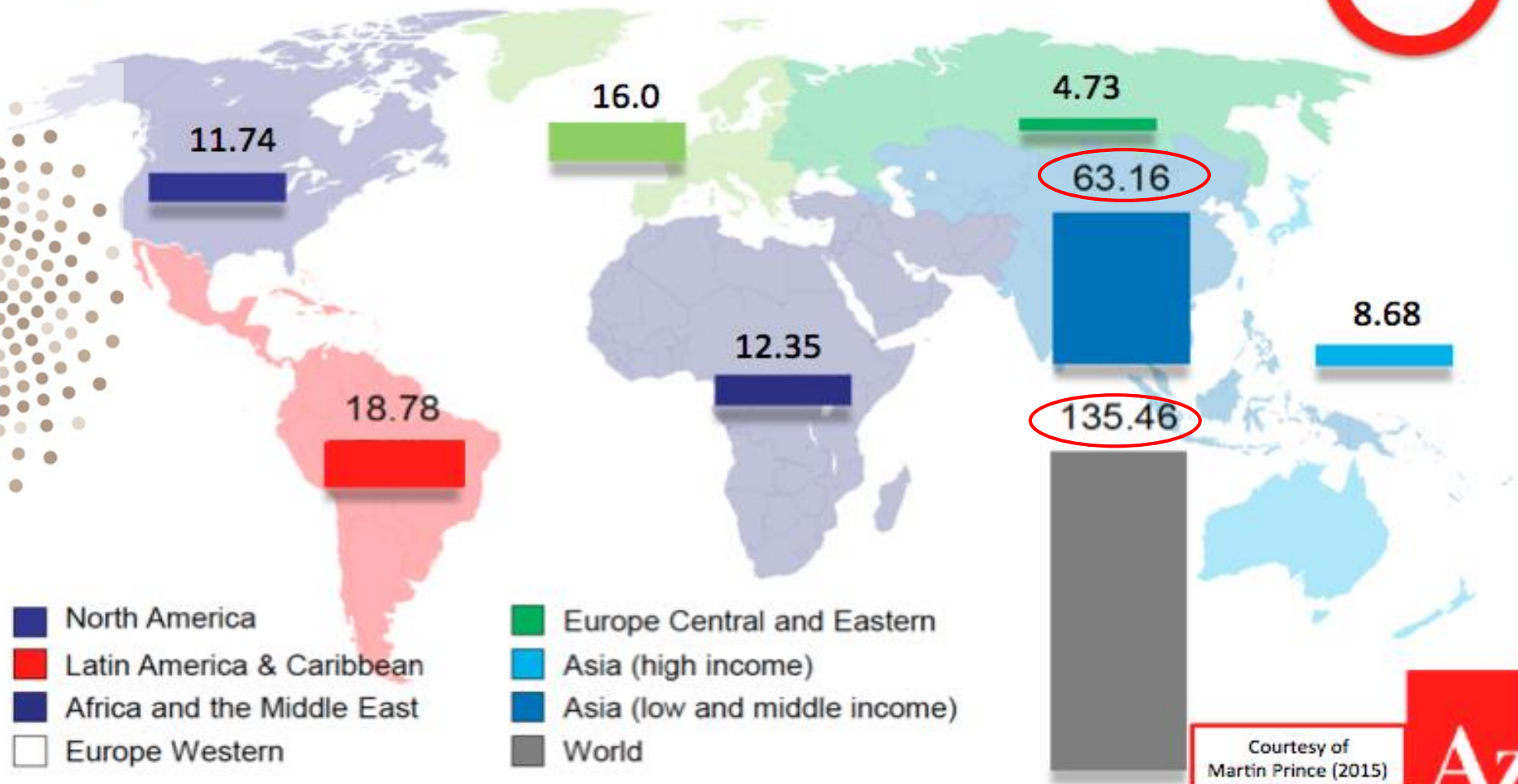
Raj Long MBPsS MSc
Vice Chair World Dementia Council
ASAD Hangzhou
October 2016

Overview

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1. Global State of Dementia
 2. World Dementia Council 2014 -2016
 3. Finding a Path Forward

Numbers of people with dementia by world region (2015-2050)

2015 2020 2025 2030 2035 2040 2045 2050



Courtesy of Martin Prince (2015)

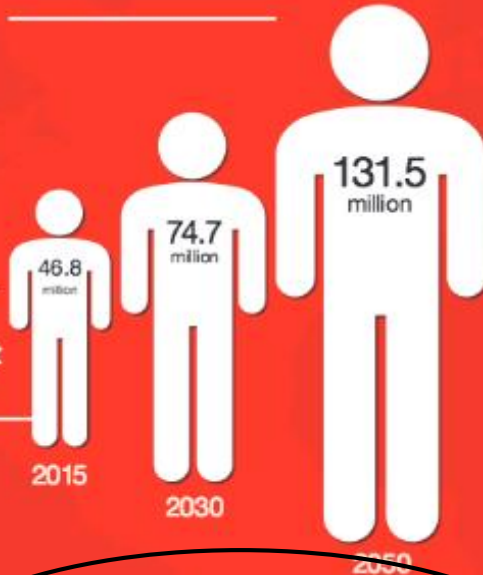


The global impact of dementia

Around the world, there will be 9.9 million new cases of dementia in 2015,

one every 3 seconds

36.8 million people worldwide are living with dementia in 2015. This number will almost double every 20 years.



Much of the increase will take place in low and middle income countries (LMICs): in 2015, 58% of all people with dementia live in LMICs, rising to 63% in 2030 and 68% in 2050.



The total estimated worldwide cost of dementia in 2015 is US\$ 818 billion. By 2018, dementia will become a trillion dollar disease, rising to US\$ 2 trillion by 2030

If global dementia care were a country, it would be the 18th largest economy in the world exceeding the market values of companies such as Apple and Google



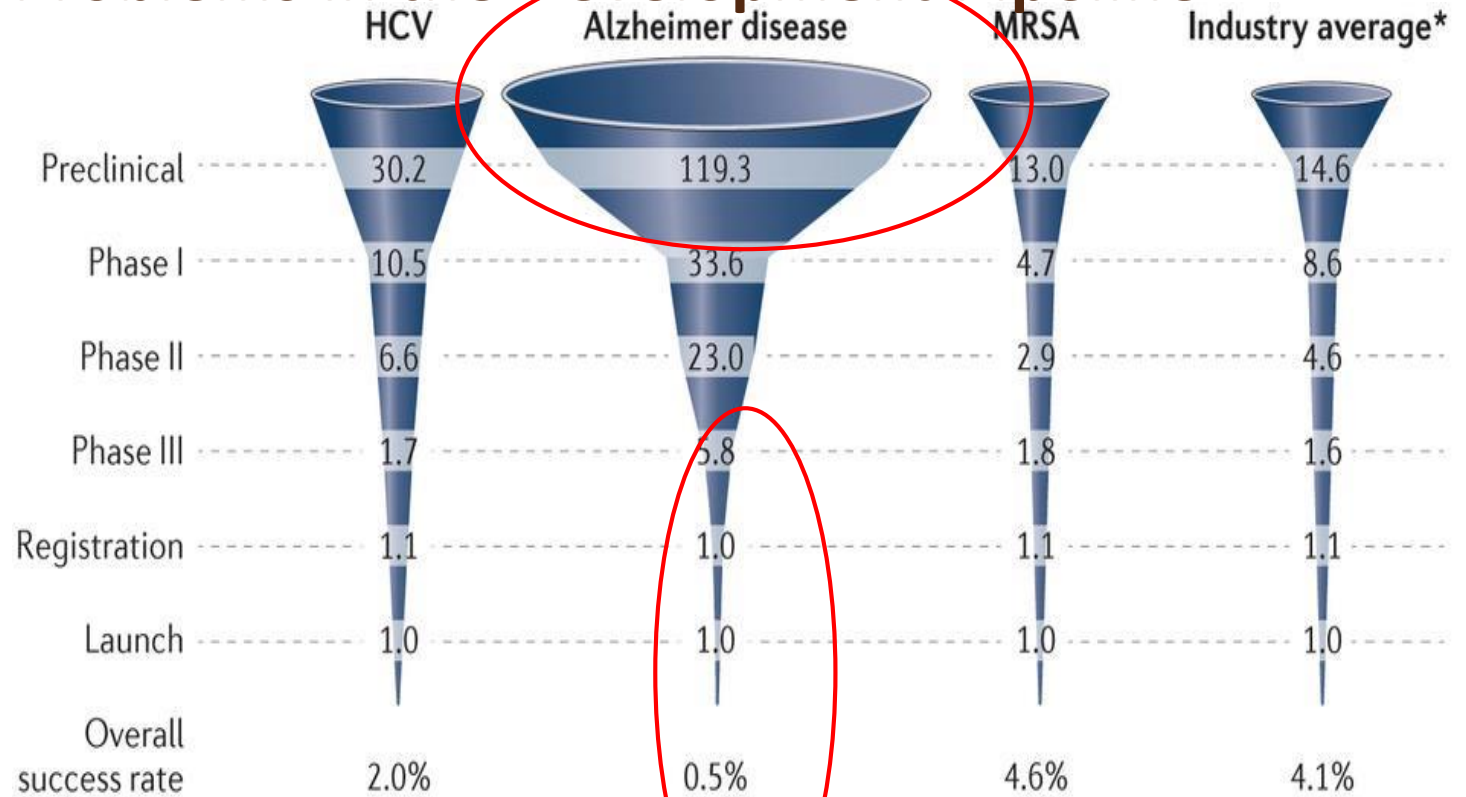
(see [Forbes 2015 ranking](#))



We must now involve more countries and regions in the global action on dementia.

The World Alzheimer Report 2015 was independently researched by King's College London and supported by Bupa.

Problems in the Development Pipeline



Nature Reviews | Drug Discovery

The Global Dementia Challenge

- Dementia is one of the biggest global challenges
- The WHO estimates dementia population is exploding
 - 2016 - over 47m
 - 2030 – 75 m
 - 2050 – over 135 m
- AD International estimate that the worldwide cost of dementia
 - 2016: approximately \$818b
 - 2018: around \$1 trillion
 - 60% of the disease burden falls on LMIC countries with least capacity

***Intensive Proliferation + No Disease Modifying Tx =
Unsustainable Model***

Driver - The World Dementia Council

- In Dec 2013, UK hosted a G8 Dementia Summit
- 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
- Goal was to bring together experts across the world to start a global conversation about solutions for dementia



"If we are to beat dementia, we must also work globally, with nations, business and scientists from all over the world working together as we did with cancer, and with HIV and AIDS. This is going to be a bigger and bigger issue; the key is to keep pushing."

David Cameron, December 11, 2013 (BBC News)

The 1st 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

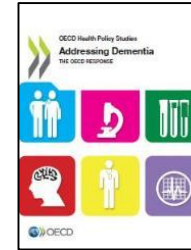
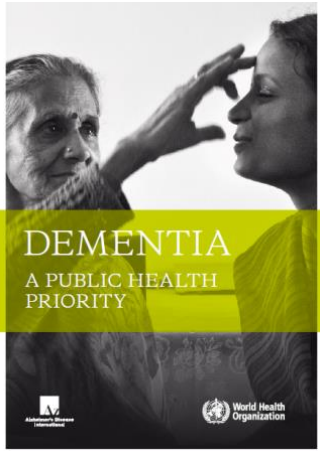


The Re-formed World Dementia Council

- The World Dementia Council re-formed and reconstituted to include a more global membership
- February 2016, in line with this independence
 - New members drawn from a range of sectors & organisations across the wider dementia community
 - WDC Chair – Yves Joanette & Vice Chair – Raj Long were appointed by its members



Global Responses to Dementia Challenge



WHO/ADI Report, 2012

WHO Director General Dec 2013

World Dementia Council 2014

OECD Report Addressing Dementia 2015

WHO 1st Ministerial Conference, March 2015

2012

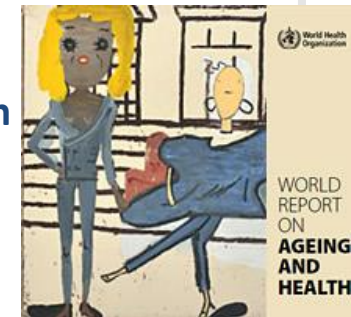
2016



UK G8 Dementia Summit Dec 2013

G7 Legacy Events UK, Canada/France, Japan, & USA 2014-15

World Health Assembly May 2016 -



Multisectoral action for a life course approach to healthy ageing

Priorities of the World Dementia Council

2014 April – 2016 Feb

The WDC members agreed to focus on the following priorities:

- Innovative and global finance models
- Integrated drug development
- Open science collaborative global research including the use of big data
- Ensuring adequate care for people living with dementia and their carers
- Facilitating the identification and the dissemination of risk reduction strategies



Progress – Finance Models

- In March 2015, the WDC helped to shape the UK Govt-led work to establish the ***Dementia Discovery Fund*** by seed funding. 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



Progress – Integrated Drug Development

- In Nov 2014, Raj Long convened 11 regulators from 10 agencies to work collaboratively on dementia & they have collectively identified 5 work streams. This the first time 10 international regulatory agencies came together to look at dementia drug development to share their experiences. Work is ongoing in 2015 and 2016
 - **Clinical Trial Efficiency**
 - **Composite Endpoints**
 - **Modelling & Simulation**
 - **Multilateral Collaboration**
 - **Risk/Benefit Ratio**
- In July 2015, WDC member Raj Long published an independent report on the dementia drug development pathway '**Finding the Path for a Cure for Dementia**' setting out key actions for change which the international community needs to implement to improve & speed up the dementia drug pathway.
- UK Government invited an international panel (approx. 20) to review the report and then formally responded

Long Report 2015: Outlining Actions for Change

Informed by over 25 years drug development experience in the pharmaceutical industry and in the regulatory strategy, combined with the insights gained over the past 18 months as ID lead and WDC member

The Report sets out issues facing dementia drug development, and provides insight based on the work to date and current publications.

It examines the data and evidence that has been collated over 18 months, culminating in a series of 'Actions for Change'.

The Report can be found here:

<https://www.gov.uk/government/publications/challenges-to-finding-treatments-for-dementia>

An Independent Report on the Global
Regulatory Approach to Achieve the
Development of Safe, Effective and
Affordable Drugs for Dementia

Executive Summary and Recommendations

Raj Long

Progress – Research/Open Science/Big Data

WDC provided input and shaped collaborative projects that are attempting to enable greater & effective data sharing.

Examples include:

- **'The development of good practices on data governance'** resulted in a report from the OECD & Oxford Internet Institute published in March 2015
- The Canadian Consortium of Neurodegeneration in Ageing (CCNA) & the Dementia Platform UK (DPUK) collaboration to create an integrated system to **share & analyse large scale & complex cohort based datasets**





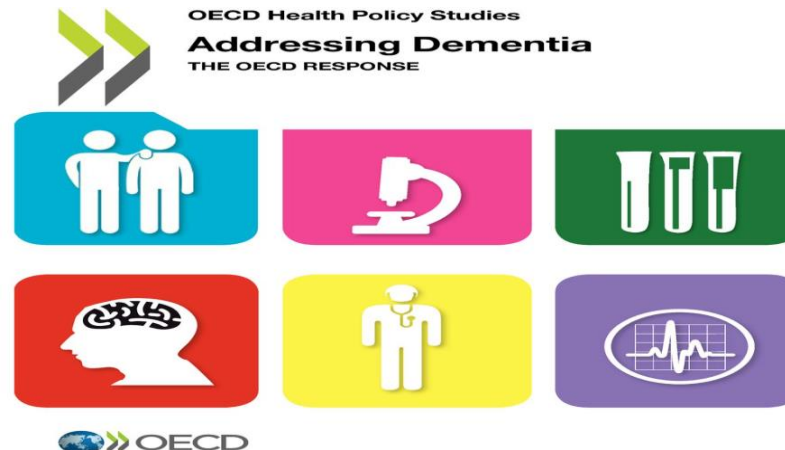
Dementia Research and Care

CAN BIG DATA HELP?



Progress – Care

- The WDC worked closely with OECD & WHO on a framework to help address the needs of people with dementia & their carers, covering prevention, diagnosis & post diagnosis care & support
- The framework was included in the OECD report **“Addressing Dementia: the OECD response”**



Progress – Risk Reduction

- WDC member Harry Johns produced an international review of the global dementia risk reduction evidence
- The Council agreed that cognitive decline at a population level may be affected by behaviour changes – **‘What is good for your heart is good for your brain’**
- Highlighted risk reduction as a key tool for adoption by governments & others to tackle dementia through the publication of a risk reduction statement



Examples of Other Global Actions

- Legacy Events with various intentional themes (2014 - 2015)
 - UK: New finance models & Social Incentives
 - Canada/France: Synergies between academia & industry
 - Japan: Prevention & care model
 - US: Alzheimer research summit
- National Dementia Plans (2015 - 2016)
 - 22 Countries with national dementia plans + 7 in development
- Brain health empowerment (2016)
 - The Global Council on Brain Health – AARP & Age UK
 - Collaboration to better understand how to improve brain health
- Japan G7 2016 in Ise-Shima and Health Ministers' meeting Ministerial in Kobe mentioned Dementia plan and WDC support



WDC Priorities 5 Point Plan – Path Forward Feb 2016

1 Finance – WDC Lead Chris Llewellyn

- 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 (e.g. Cancer, HIV) that could be applied to dementia
- Convene key figures and stakeholders to address funding disparities by influencing funder decisions

Integrated Development ACCESS - WDC Lead Raj Long

- ### **2**
- Facilitate a pathway for access through readiness for wide spread adoption of new treatments in dementia.
 - Develop a robust strategy for engaging payer groups - taking into account different models that exist (e.g. varying guidelines, expectations etc.)
 - Identify strategic drivers for access to dementia treatments and to support adoption of the plan



WDC Priorities 5 Point Plan – Path Forward Feb 2016

3 Risk Reduction - WDC Lead Ron Peterson

- 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.

4 Care - WDC Lead Harry Johns

- Create and distribute a bold Word Dementia Council statement around the importance of, and principles for good dementia care
- Identify gaps in current knowledge around dementia care, with greatest potential for generating maximum impact for people with dementia and their caregivers



WDC Priorities 5 Point Plan – Path Forward Feb 2016

5 Research/Open Science/Data - WDC Lead Phillipe Amouyel

- Facilitate the global expansion of funding programmes such as the EU Joint Programme in Neurodegenerative Diseases (JPND)
- 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

WHO – Global Dementia Observatory

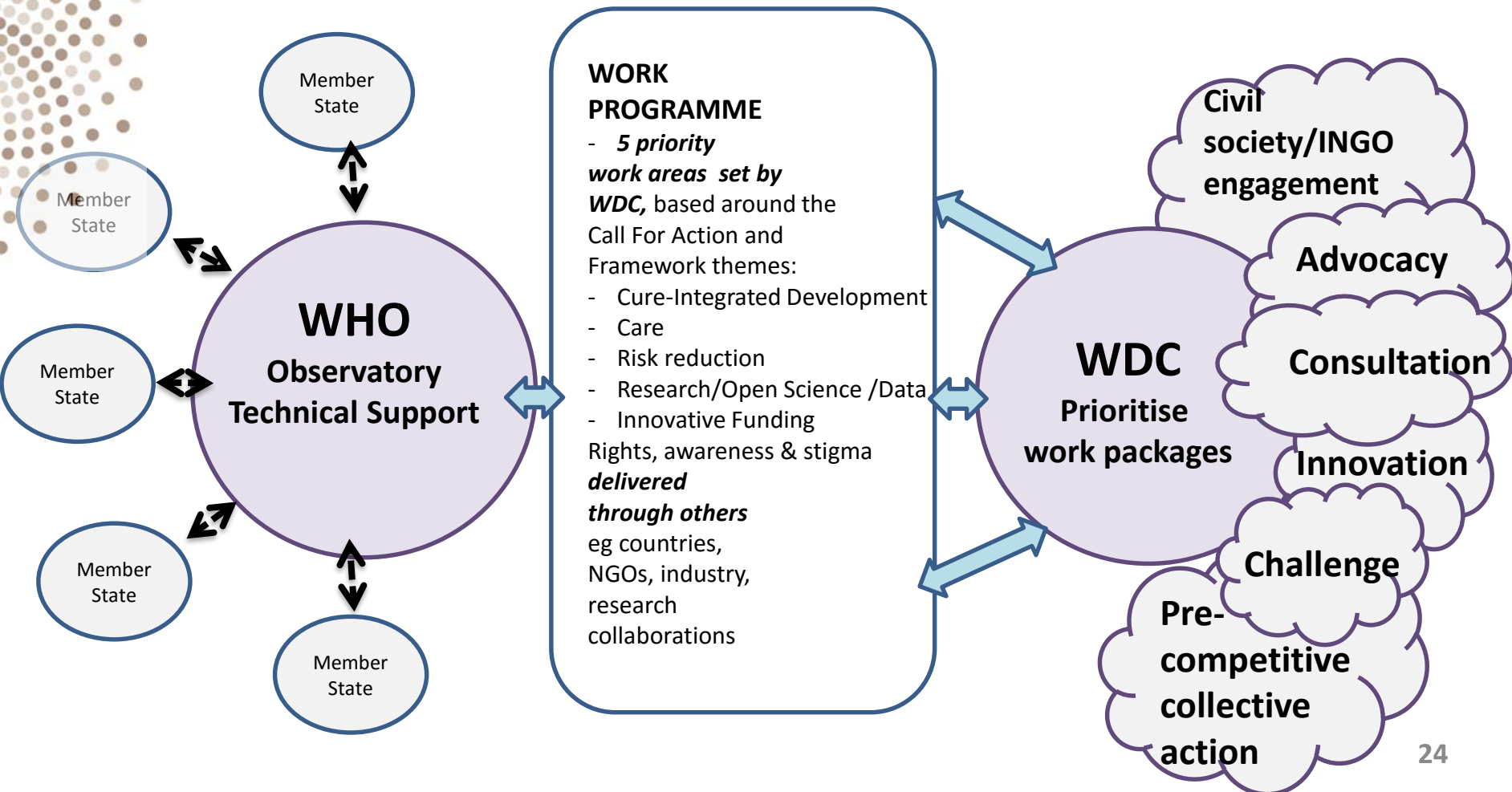
- To help countries to support individuals with dementia and to reduce the disease burden and cost
- To better understand countries' needs for evidence-based service planning and policies and to strengthen their capacity
- To monitor progress within countries and globally
- To share best practices and create a knowledge exchange platform

Several WDC members serve in the WHO GDO
WHO is member of the WDC

No formal governance between these two pillars, but a collaborative approach to optimize global impact



WHO/WDC Bi-Partite Model



The World Dementia Council Moving Forward

- The **5 Global Teams** made up of Council Members and other experts will move forward on all five priorities with 6, 12, 18 month deliverables
- The **WHO Global Dementia Observatory**
 - Mutual leverage
 - Push and Pull from both modalities
 - WHO – bringing together Member States and supporting the Global Dementia Observatory
 - The World Dementia Council - providing a complementary role of a confluence multi stakeholders groups in order to support, amplify and coordinate a global response

WHO Director General, Dr Margaret Chan, Dec 2013

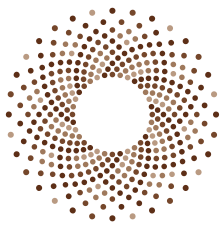


“I can think of no other condition where innovation, including breakthrough discoveries, is so badly needed”

Quote: M. Chan Dec 2013

“ We must think outside the box, it cannot be business as usual. If we don't have the passion to break the mould, it won't happen. We must have the will and the state of mind to take on the challenge of this disease as a global community”

R. Long Oct 2016



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Thank You

info@worlddementiacouncil.com

Raj Long October 2016