



**NAEC Seminar: Addressing
Dementia
27 February 2017**

**CONTRIBUTING TO
BETTER CARE, RESEARCH
AND INNOVATION**

The OECD's work on dementia



1. MEASURING PERFORMANCE IN DEMENTIA CARE



OECD/WHO framework provides a starting point about what to measure

Risk reduction



The risk of people developing dementia is minimised

1



First symptoms appear

Diagnosis



Dementia is diagnosed quickly once someone becomes concerned about symptoms

2

Care coordination and the role of technology



Care is coordinated, proactive and delivered closer to home

9



The potential of technology to support dementia care is realised

10

Progression of dementia

Early dementia

Living in the community and relying on informal care



Communities are safer for and more accepting of people with dementia

3



Those who wish to care for friends and relatives are supported

4

Advanced dementia

Greater need for formal care services and specialised accommodation



People living with dementia live in safe and appropriate environments

5



People living with dementia can access safe and high quality social care services

6



Health services recognise and effectively manage people living with dementia

7

End of life

End of life care for people with dementia presents specific challenges



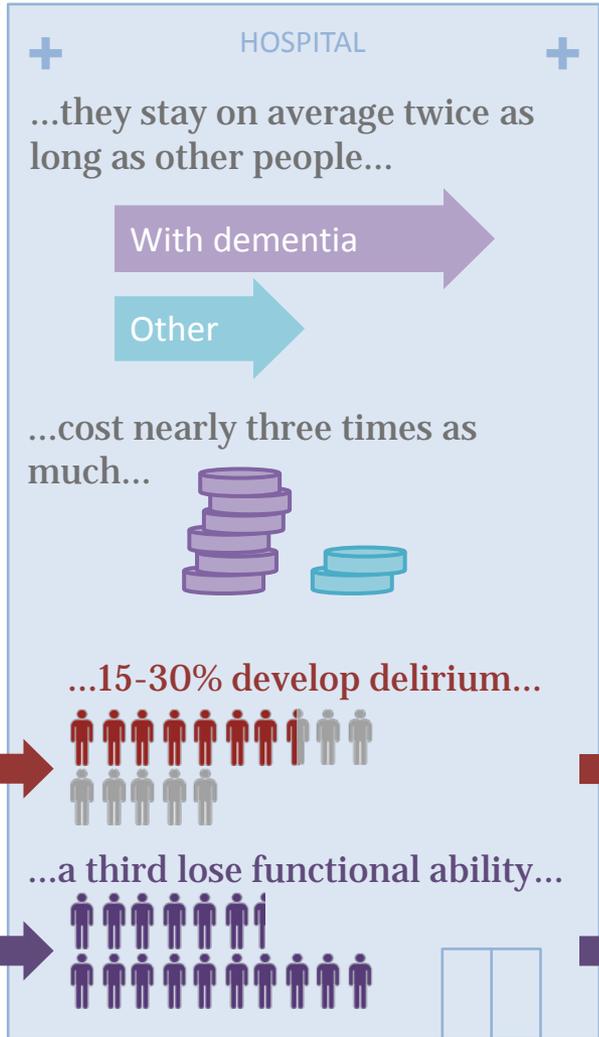
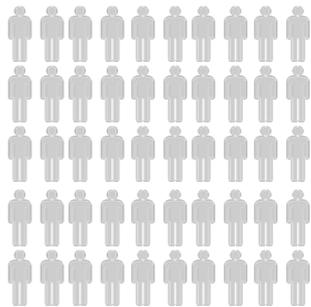
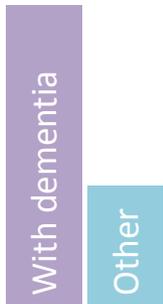
People living with dementia die with dignity in the place of their choosing

8



Outcomes for people with dementia in hospital are often very poor

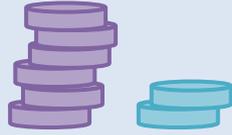
People with dementia are 2-3 times as likely to be admitted to hospital...



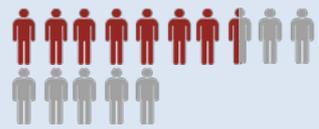
...they stay on average twice as long as other people...



...cost nearly three times as much...



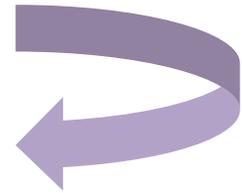
...15-30% develop delirium...



...a third lose functional ability...



...and are more likely to be readmitted.



...and one in five of them still have symptoms six months later.



...and half of them never recover these abilities.





The misuse of antipsychotics is widespread in care homes

Percentage of long-term care home residents 65 years or older who were using antipsychotic medication with a diagnosis of a specific medical condition on March 31, 2013, in Ontario



 Residents with psychosis

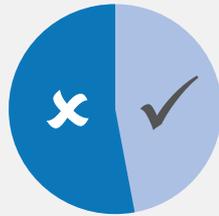
 Residents with dementia (without psychosis)

 Residents without documented diagnosis of psychosis or dementia

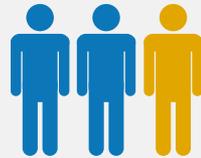
 With a prescription for an antipsychotic medication



We also know that care in the community can be inadequate



More than half of all people with dementia **undiagnosed**



One in three only **leave the house once a week**



Carers 20% more likely to have **mental health** problems



We are piloting indicators of dementia care to drive quality improvement



Indicators of the quality of hospital care

% of hip fracture surgery initiated within two days for people with dementia

Average length of stay for hip fracture surgery for people with dementia

30-day and 1-yr mortality following hip fracture surgery for people with dementia



Indicators of the quality of long-term / community care

Hospital admission rate for people with dementia

Hospital admission rate for hip fracture for people with dementia

% of over-65s prescribed antipsychotics in the past year



In the longer term, patient-reported measures will be essential

PaRIS will...

Accelerate and standardise international monitoring, in population groups where patient-reported indicators are already used.

- **Priority groups** will be patients who have experienced stroke, heart attack, cancer, hip and knee surgery, and mental illness.
- **Close collaboration** with international partners such as The Commonwealth Fund and the International Consortium for Health Outcomes Measurement will ensure state of the art indicators and surveys.

Develop new patient-reported indicators in critical areas of health care, where none currently exist.

- **Priority groups** in this case are patients with complex, long-term conditions such as diabetes or dementia and – in particular – patients with several conditions.
- **We will survey these patients and carers directly**, and publish new international benchmarks of health system performance.



2. USING BIG DATA TO IMPROVE CARE AND HELP DEVELOP A CURE

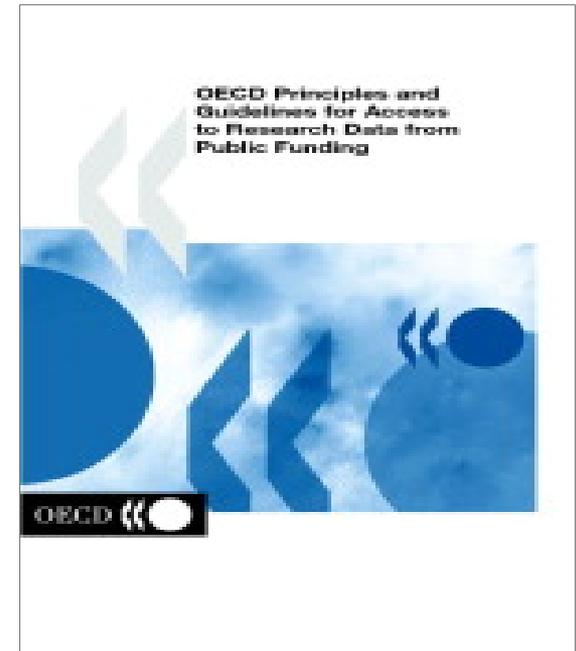


Data is at the Basis of Dementia Research – Improving Access is Key

Combining broad (population) and deep (clinical, e.g. genetic imaging) data on dementia can **enhance understanding** of dementia, as a very complex set of diseases.

Need for **action from funding agencies and policy makers**, e.g. as regards funding or privacy frameworks. Existing policy principles need updating.

Also scope for principles for data sharing **relying on the researcher community**.





OECD Draft Recommendation on Health Data Governance - Scope

- » Focus on areas where there is widely recognized, obvious and substantial public interest in health research, health care and health system improvements
- » Acknowledge the continuum of health data use and adopt a broad definition of health data
- » Build on the 2013 OECD Privacy Guidelines, the 2015 Recommendation on Digital Security Risk Management and other relevant frameworks
- » Also draws on work of the OECD Health Committee on data governance mechanisms



Some key principles for better health data governance

Engagement and participation

Coordination and cooperation

Capacity of public sector health data systems

Clear provision of information

Effective consent and choice mechanisms

Controls and safeguards

Approval procedures for the use of personal health data

Public disclosure and transparency

Recognition of the role of technology

Monitoring and evaluation mechanisms

Training and skills development in privacy and security

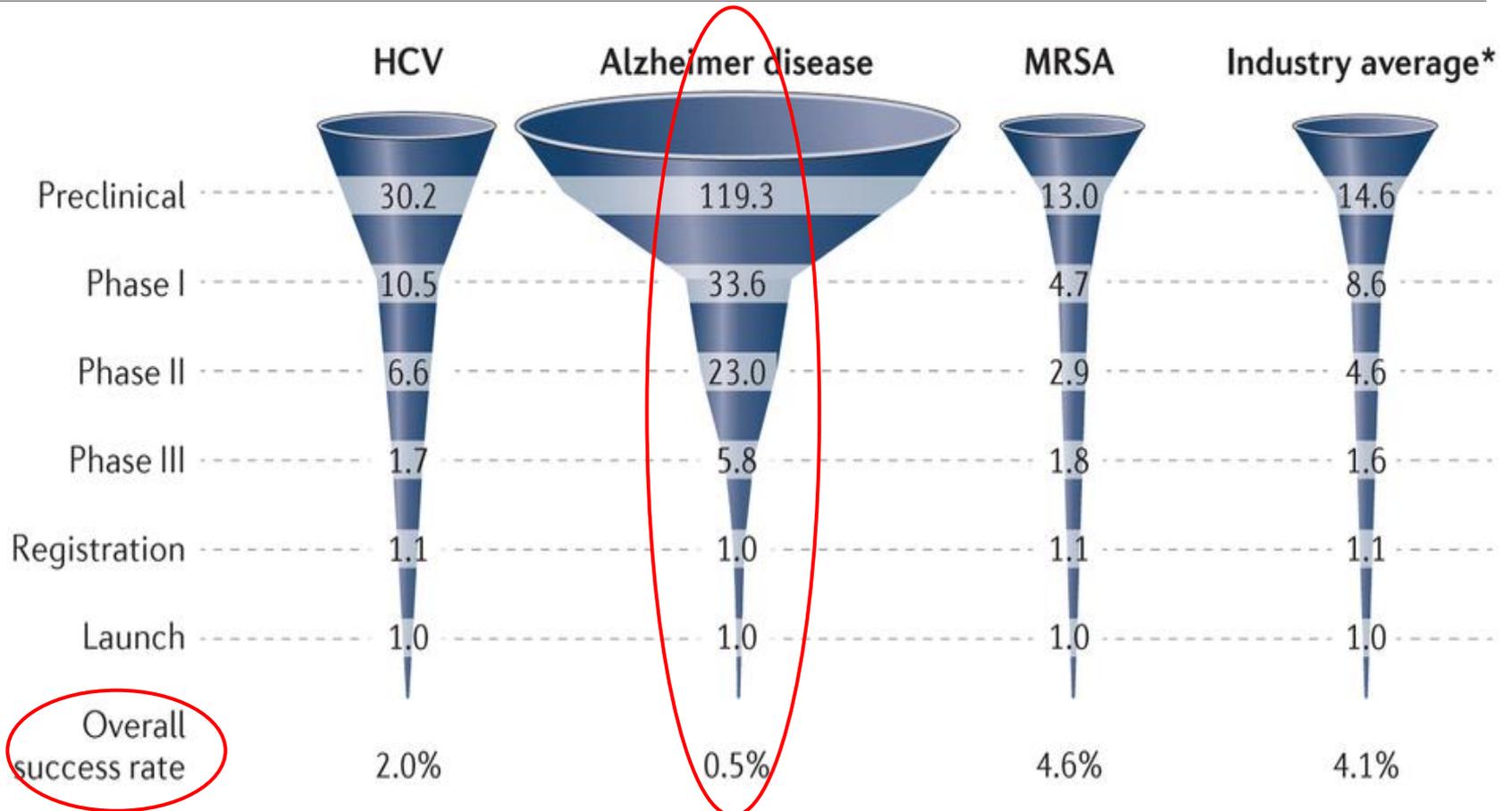
Certification or accreditation



3. RESEARCH AND INNOVATION



Problems in the development pipeline





OECD Support for Work with Regulators on Integrated Development



10th Nov 2014 (Geneva) 1st Global Dementia Regulators Workshop

11 regulators from 10 agencies including the US, EU, Canada, Japan, Switzerland, Germany, Italy, Denmark, the Netherlands, clinical experts WHO, OECD and a patient representative

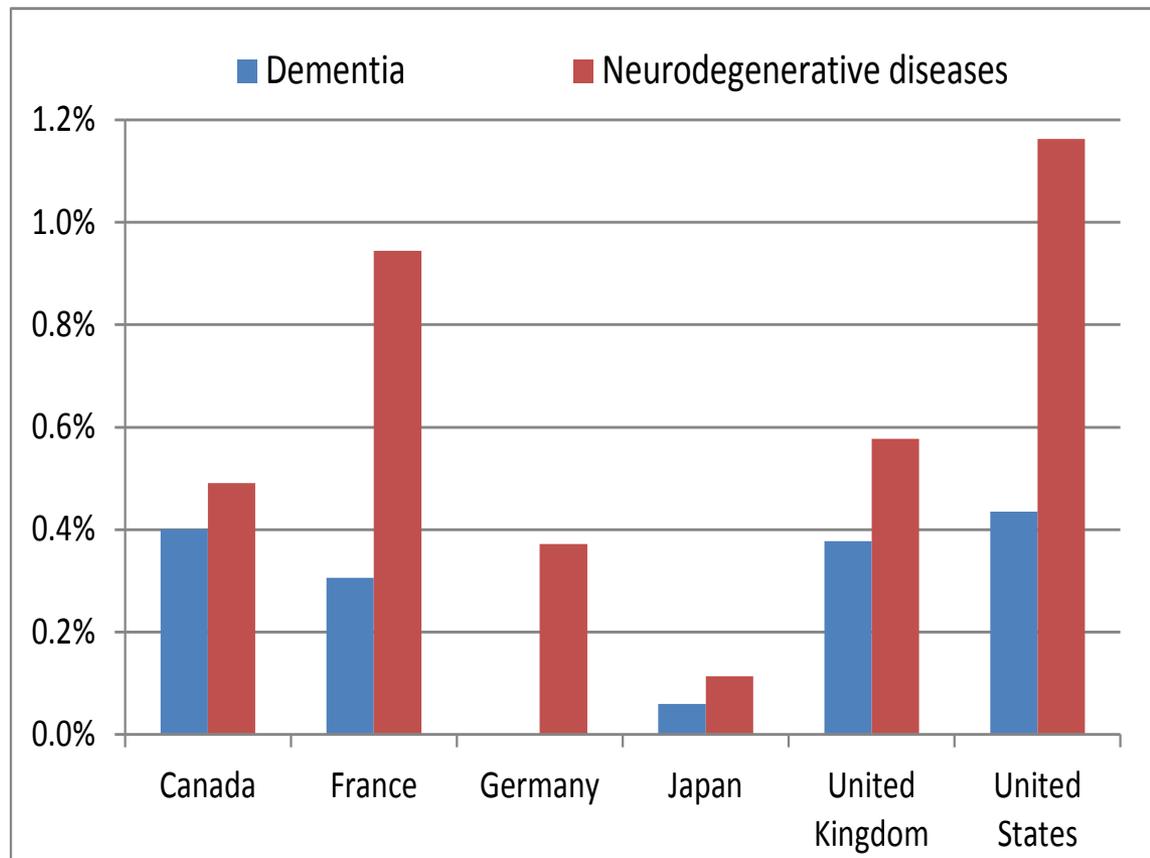


- Global Initiative - First time 10 agencies converged to look at Dementia
- Outcome: Identified 6 potential key work areas - led by Regulators
- Follow up meetings in June 2015, 28-29 June 2016, and November 2017 (t.b.c.)



In 2012, public investment in dementia research in G7 countries accounted for less than 0.5% of government R&D

R&D budgets dedicated to dementia and other neurodegenerative diseases, 2012
As a percentage of government budgets for R&D



Total Public investment of G7 countries in dementia R&D in 2012: just over **800 million USD**

Total global public investment below 1.5 billion USD.



3rd Annual Lausanne Workshop



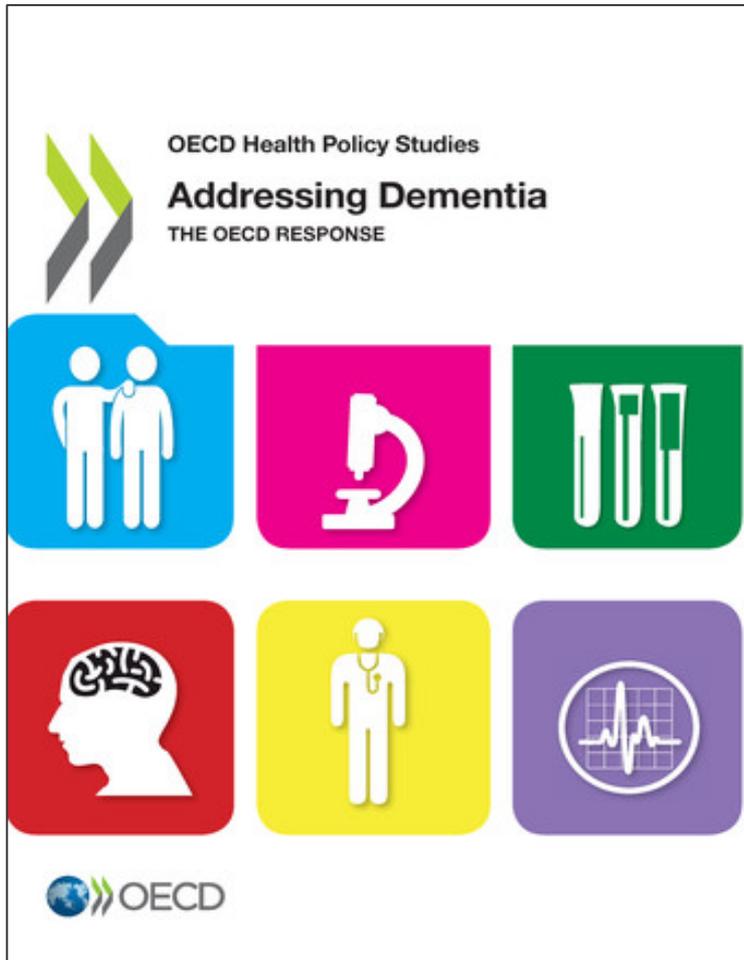
THE ROAD TO 2025: Delivering Next Generation Alzheimer's Treatments

27-28 October 2016
Lausanne, Switzerland

Increasing Understanding and Collaboration Between
Industry, Regulators and Payers



Thank you



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