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.
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... 

...and are more likely to be readmitted.

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

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

Source: studies from various OECD countries
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:

- 47.2% of residents with psychosis have a prescription for antipsychotic medication.
- 26.9% of residents with dementia (without psychosis) have a prescription for antipsychotic medication.
- 12.0% of residents without dementia or psychosis have a prescription for antipsychotic medication.

Legend:
- Green: Residents with psychosis
- Purple: Residents with dementia (without psychosis)
- Light blue: Residents without documented diagnosis of psychosis or dementia
- Dark blue: 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 are undiagnosed.
- One in three carers only leave the house once a week.
- Carers are 20% more likely to have mental health problems.

Sources: various studies from different OECD countries
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
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.
Need for good practices and better data governance

Structural challenges to data sharing
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

<table>
<thead>
<tr>
<th>Engagement and participation</th>
<th>Approval procedures for the use of personal health data</th>
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<tbody>
<tr>
<td>Coordination and cooperation</td>
<td>Public disclosure and transparency</td>
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<tr>
<td>Capacity of public sector health data systems</td>
<td>Recognition of the role of technology</td>
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<tr>
<td>Clear provision of information</td>
<td>Monitoring and evaluation mechanisms</td>
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<tr>
<td>Effective consent and choice mechanisms</td>
<td>Training and skills development in privacy and security</td>
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<td>Controls and safeguards</td>
<td>Certification or accreditation</td>
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3. RESEARCH AND INNOVATION
### Problems in the Development Pipeline

<table>
<thead>
<tr>
<th>Stage</th>
<th>HCV</th>
<th>Alzheimer Disease</th>
<th>MRSA</th>
<th>Industry Average</th>
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</thead>
<tbody>
<tr>
<td>Preclinical</td>
<td>30.2</td>
<td>119.3</td>
<td>13.0</td>
<td>14.6</td>
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<tr>
<td>Phase I</td>
<td>10.5</td>
<td>33.6</td>
<td>4.7</td>
<td>8.6</td>
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<tr>
<td>Phase II</td>
<td>6.6</td>
<td>23.0</td>
<td>2.9</td>
<td>4.6</td>
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<tr>
<td>Phase III</td>
<td>1.7</td>
<td>5.8</td>
<td>1.8</td>
<td>1.6</td>
</tr>
<tr>
<td>Registration</td>
<td>1.1</td>
<td>1.0</td>
<td>1.1</td>
<td>1.1</td>
</tr>
<tr>
<td>Launch</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
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<tr>
<td><strong>Overall success rate</strong></td>
<td><strong>2.0%</strong></td>
<td><strong>0.5%</strong></td>
<td><strong>4.6%</strong></td>
<td><strong>4.1%</strong></td>
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</tbody>
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*Nature Reviews | Drug Discovery*
OECD Support for Work with Regulators on Integrated Development

10\textsuperscript{th} Nov 2014 (Geneva) 1\textsuperscript{st} 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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