QUALITY INDICATORS FOR DEMENTIA

The case for exploring this area and some initial thoughts on what could be done
Ageing populations mean dementia is becoming more common.

Dementia prevalence in Europe by age band

*assumed constant over time*

The number of people with dementia in Europe by age and year

*Source: OECD analysis of data from Alzheimer's Europe and the United Nations*
The international community has been focusing on dementia

G8 Summit  
*December 2013, London*

- Global events
  - Toronto, Sep 14
    - OECD hosted event on how big data can support research and care
  - Japan Legacy Event, Nov 14
    - OECD produced review of policies for dementia care

- Publications
  - Can big data help?
    - We published the proceedings of the Toronto workshop
  - Addressing Dementia
    - OECD publication bringing together work on care, research and big data

- World Dementia Council
  - Joint OECD / WHO paper on care led to it being adopted as a formal objective of the Council

WHO conference  
*March 2015, Geneva*

- OECD supported this conference and produced a joint OECD / WHO framework for improving policies around dementia care.

What next?  
Strong interest from countries and other organisations in *measuring and comparing performance*
OECD/WHO framework identifies ten key objectives for dementia policy

**Risk reduction**
- The risk of people developing dementia is minimised

**Diagnosis**
- Dementia is diagnosed quickly once someone becomes concerned about symptoms

**Progression of dementia**

1. **First symptoms appear**
2. **Dementia is diagnosed**
3. **Communities are safer for and more accepting of people with dementia**
4. **Those who wish to care for friends and relatives are supported**
5. **People living with dementia live in safe and appropriate environments**
6. **People living with dementia can access safe and high quality social care services**
7. **Health services recognise and effectively manage people living with dementia**
8. **People living with dementia die with dignity in the place of their choosing**
9. **Care is coordinated, proactive and delivered closer to home**
10. **The potential of technology to support dementia care is realised**

**Care coordination and the role of technology**
- Care is coordinated, proactive and delivered closer to home
- The potential of technology to support dementia care is realised
OECD/WHO framework identifies ten key objectives for dementia policy

Risk reduction
- The risk of people developing dementia is minimised

First symptoms appear

Diagnosis
- Dementia is diagnosed quickly once someone becomes concerned about symptoms

Progression of dementia

Early dementia
- Living in the community and relying on informal care

Advanced dementia
- Greater need for formal care services and specialised accommodation

End of life
- End of life care for people with dementia presents specific challenges

1. Care coordination and the role of technology
   - Care is coordinated, proactive and delivered closer to home
   - The potential of technology to support dementia care is realised

2. Dementia is diagnosed quickly once someone becomes concerned about symptoms

3. Communities are safer for and more accepting of people with dementia

4. Those who wish to care for friends and relatives are supported

5. People living with dementia live in safe and appropriate environments

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

7. Health services recognise and effectively manage people living with dementia

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

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

10. People living with dementia die with dignity in the place of their choosing
We are failing to meet the needs of people with dementia and their carers

- More than half of all people with dementia are undiagnosed.
- A third of those in care homes are on antipsychotics.
- One in three only leave the house once a week.
- Carers are 20% more likely to have mental health problems.
- Hospital costs are three times higher than for other people.
- A third come out of hospital with reduced functional ability. Half of these people never recover.
What indicators are currently available?

### Managing behavioural symptoms
- Use of physical restraints
  *US, Canada, Netherlands, Korea*

- Use of antipsychotics
  *Canada, Netherlands*

- HCQI work on use of benzodiazepines in over-65s

### General LTC indicators
- Prevalence of pressure ulcers
  *US, Canada, Netherlands, Korea, Portugal*

- Prevalence of UTI in care homes
  *US, Canada Korea*

- Very few dementia-specific indicators
- Very few indicators on LTC more broadly
- Limited country coverage and variations in definitions
What do we want to measure and what is stopping us?

- Diagnosis rates / stage of dementia at diagnosis
  - Diagnoses not always systematically recorded

- Quality of life for people with dementia and carers
  - Inherently difficult to measure (use surveys?)

- ACS admissions for people with dementia
  - We measure these things already but it is difficult to identify people with dementia in the data

- Readmission rates for people with dementia

- Place of death for people with dementia
  - Hard to link diagnoses of dementia to death records
What could be done to improve the situation?

**Better recording of diagnoses**
- Consistent diagnosis procedure using a robust tool such as InterRAI
- Single place for recording all diagnoses (e.g. Swedish dementia registry)
- More consistent coding of dementia in hospitals

**Better linking of data**
- All relevant data stored on dementia registry
- Electronic health records
- Linking of health and social care data (and other sources)
Questions for discussion

• Is this an area that this group should focus on over the next year or two?
• What can this group do to drive forward this agenda?
  – e.g. A comprehensive review of what is currently collected in member countries
  – Identify small changes that countries can make to improve data