DIGNITY IN DEMENTIA

How better policy can improve the lives of people with dementia

Mark Pearson
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THE CASE FOR POLICY ACTION
Dementia is the fastest growing major cause of disability in the world today...

Years lost due to disability from major* causes, all ages

Source: WHO Global Health estimates 2014
* “Major” means causes contributing more than 1% of the total global burden of disability
…and is already the second biggest cause of disability for the over-70s

Years lost due to disability from major* causes, over-70s

Source: WHO Global Health estimates 2014

* “Major” means causes contributing more than 1% of the total global burden of disability for over-70s
The increase in burden of disease is due to ageing populations…

Proportion of the population over 80

Source: UN World Population Prospects, 2012 revision
...and the fact that dementia prevalence is strongly linked to age.

Dementia prevalence in Europe by age and the additional number of people with dementia as a result of ageing in the last 20 and next 20 years

Source: OECD analysis of data from Alzheimer's Europe and the United Nations
The financial cost of dementia is a major issue globally.

Cost of dementia (US$, 2013 prices)

- Europe (2008): $213bn
- Canada (2011): $28bn
- UK (2014): $38bn
- Ireland (2010): $2bn

Sources: Wimo, A. et al. (2013); Wimo, A. et al. (2011); Connolly, S. et al. (2014); Prince, M., Knapp, M. et al. (2014); Hurd et al. (2013); Canadian Institutes of Health Research
The financial cost of dementia is a major issue globally

Cost of dementia (US$, 2013 prices)

- World (2010): $645bn
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These three facts mean that dementia should be a global policy priority

1. Dementia has a large human cost
2. Dementia has a large financial cost
3. Both of these costs are growing
HOW CAN DEMENTIA POLICY BE IMPROVED?
Country strategies should be supported by international collaboration

**International resources**

1. Priority areas and key objectives
2. Policy options and evidence
3. Metrics for measuring progress
4. Key enablers of measurement

**Country-specific improvement activities**

- Develop policies
- Implement policies
- Evaluate and refine policies
- Measure and benchmark
- Develop data systems to enable measurement
- Research on dementia care and prevention

• Identify relevant improvement areas
• Learn from other countries
• Collect comparable data

Feed back learning to the international community
Countries need to focus on evaluating and improving policies

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Feed back learning to the international community
There are four key ways international collaboration can support countries:

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*Feed back learning to the international community*
We have identified ten key objectives for dementia policy in OECD countries:

1. Prevention (out of scope)
   - The risk of people developing dementia is minimised

2. Diagnosis (chapter 3)
   - Dementia is diagnosed quickly once someone becomes concerned about symptoms

3. Early dementia (chapter 4)
   - Living in the community and relying on informal care
   - Communities are safer for and more accepting of people with dementia
   - Those who wish to care for friends and relatives are supported

4. Advanced dementia (chapter 5)
   - Greater need for formal care services and specialised accommodation
   - People with dementia live in safe and appropriate environments
   - Formal care services are safe and of a high quality

5. End of life (chapter 5)
   - End of life care for people with dementia presents specific challenges
   - People with dementia die with dignity in the place of their choosing

6. Care coordination and the role of technology (chapter 6)
   - Care is coordinated, proactive and delivered closer to home
   - The potential of technology to transform dementia care is realised

7. Health facilities recognise and effectively manage dementia patients

Progression of dementia:

- First symptoms appear
- Store
- Early dementia
- Advanced dementia
- End of life
- Health facilities

The potential of technology to transform dementia care is realised.
This presentation will focus on four areas where progress is needed

### Prevention (out of scope)
- The risk of people developing dementia is minimised

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### Progression of dementia

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- Those who wish to care for friends and relatives are supported
- Health facilities recognise and effectively manage dementia patients
- Forming care services are safe and of a high quality
- People with dementia live in safe and appropriate environments
- People with dementia die with dignity in the place of their choosing
- Communities are safer for and more accepting of people with dementia
- Dementia is diagnosed quickly once someone becomes concerned about symptoms
TIMELY DIAGNOSIS
## Diagnosis should be available to those who are concerned about symptoms

### Benefits and disbenefits to people with dementia of diagnosis at different stages

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Those concerned about symptoms should be diagnosed

All cases of advanced dementia should be diagnosed
A number of countries are focusing on increasing diagnosis rates

Diagnosis rates are low:

**England**: fewer than half of all people with dementia have a diagnosis

**Germany**: 44.5% of care home residents with dementia have no diagnosis

Different strategies for increasing rates:

**Scotland**
- Supporting local health systems to make improvements
- Diagnosis rates increased from 40% in 2008 to 67% now

**England**
- Aiming to achieve a similar improvement
- Using financial incentives for GPs
SUPPORTING INFORMAL CARERS
Most OECD countries are moving towards more community care…

Proportion of LTC users living in the community

Source: OECD Health Statistics 2014
...but this puts a significant burden on informal carers.

Estimated value of formal and informal services for people with dementia in the United Kingdom in 2015 (2012 prices)

So policies to support carers are more important than ever

**Respite care**
- At home, day care centres or temporary institutional care
- Available but underused?
- **Netherlands:** farms provide day care for people with dementia

**Counselling and support**
- Can be effective at relieving stress
- Include peer support, e.g.
  - dementia cafés in **Japan**
  - NHS Dementia Carers’ Support Service in **England**

**Information and training**
- Provide skills to care effectively and minimise negative impacts
- e.g. **France:** carers entitled to two days of training per year.
- Phone advice services, such as “Dementia Link” in **Canada**

**Help with employment**
- **Germany:** “family caring time” law helps carers reduce hours temporarily
- **Canada:** bringing together employers to explore how to help carers to keep working
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
Better identification and management of dementia in hospitals is needed

**Identifying dementia**
- Half of dementia patients not identified in some countries
- No systems for sharing diagnoses between departments in many hospitals

**Providing appropriate care**
- Managing risks such as delirium, distress and pressure ulcers

**Information sharing** can identify existing diagnoses

**Consistent recording of diagnoses** across health and care system is also essential

**Consultation and liaison services** can reduce the risk of depression.

**Specialist wards** can lead to shorter stays, better outcomes and better experiences.

There are examples of good practice, but all OECD countries should aim to implement these measures in all hospitals.
THE ROLE OF TECHNOLOGY
Despite promising examples, dementia care technology is not widely used.

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<th>Promoting social interaction</th>
<th>Managing medical needs</th>
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| • e.g. Paro robot in **Japan** | • Automated dispensers to reduce medication error (e.g. **Germany**)
| • Randomised clinical trial planned in the Netherlands | • **Telehomecare nurses** in **Canada** provide remote support |

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<td>• Reduce manual lifting and the risk of injury</td>
<td>• <strong>ComfortZone</strong> in the <strong>United States</strong> provides tracking devices</td>
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<td>• <strong>British Columbia (Canada)</strong> aims to eliminate manual lifting</td>
<td>• The <strong>Independent Project</strong> in <strong>Europe</strong> is piloting alarms, fall detectors and gas detectors.</td>
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We must address three key barriers to the development of care technologies:

1. User-focused development
   - Some technologies do not currently address the priorities of people with dementia
   - Developers need to work closely with users

2. Robust, independent evaluation
   - Too few robust trials of current technologies
   - Essential to give care systems the confidence to implement new technologies

3. Clear reimbursement criteria
   - Most care systems have not set out criteria.
   - Would give manufacturers the confidence to invest in development

Care technology assessment processes, mirroring the health technology assessments that already exist in many countries, could address points 2 and 3.
MEASURING PERFORMANCE
Improving the measurement of dementia should be a priority

- There are currently few internationally comparable measures of dementia outcomes and the impact of policy.
- Changing this should be a priority for countries and the international community.
- This event provides an opportunity to start a conversation about measurement.

**Key enablers of measurement:**

- Improving diagnosis rates and recording
- Consistent identification and coding of dementia in health facilities
- Linking data across health and care systems using EHRs or registries

**Possible measures:**

- Initial suggestions in our paper
- More work needed to refine the list and build consensus
CONCLUSIONS
Conclusions

• Need an international framework for understanding performance and holding each other to account for improvements.

• Supported by four elements:
  1. Objectives of dementia policy
  2. Evidence on policy approaches
  3. Metrics for measuring performance
  4. Enablers of measurement

• More work is needed to develop the framework and build international consensus.

• We need to start a conversation about measurement – both what we want to measure and how we can do it.
Thank you

Contact: mark.pearson@oecd.org

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Website: www.oecd.org/health