



G7 dementia legacy event
Japan
6th November 2014

DIGNITY IN DEMENTIA

How better policy can improve the lives of people with
dementia

Mark Pearson
Deputy Director
Directorate for Employment, Labour and Social Affairs

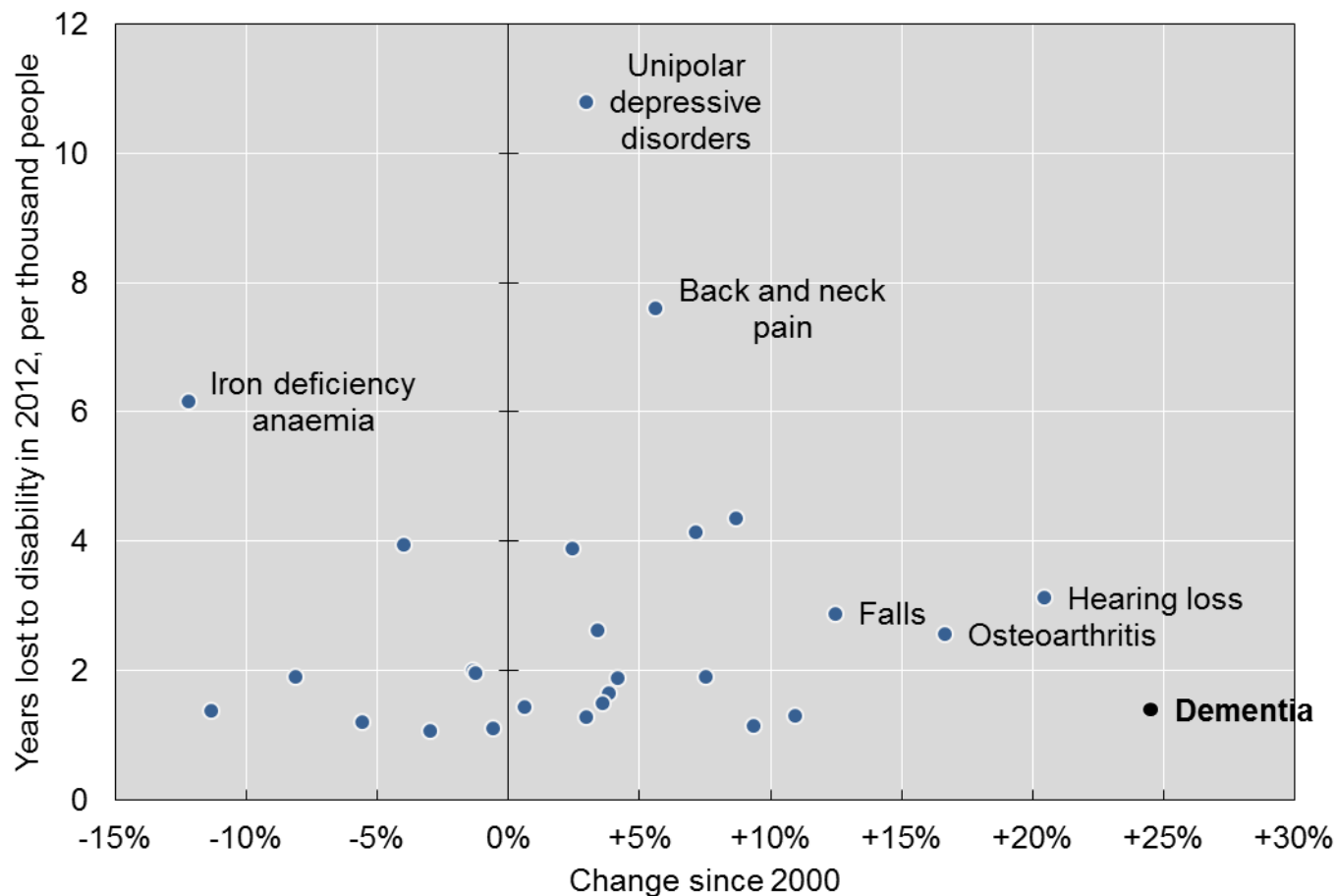


THE CASE FOR POLICY ACTION



Dementia is the fastest growing major cause of disability in the world today...

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



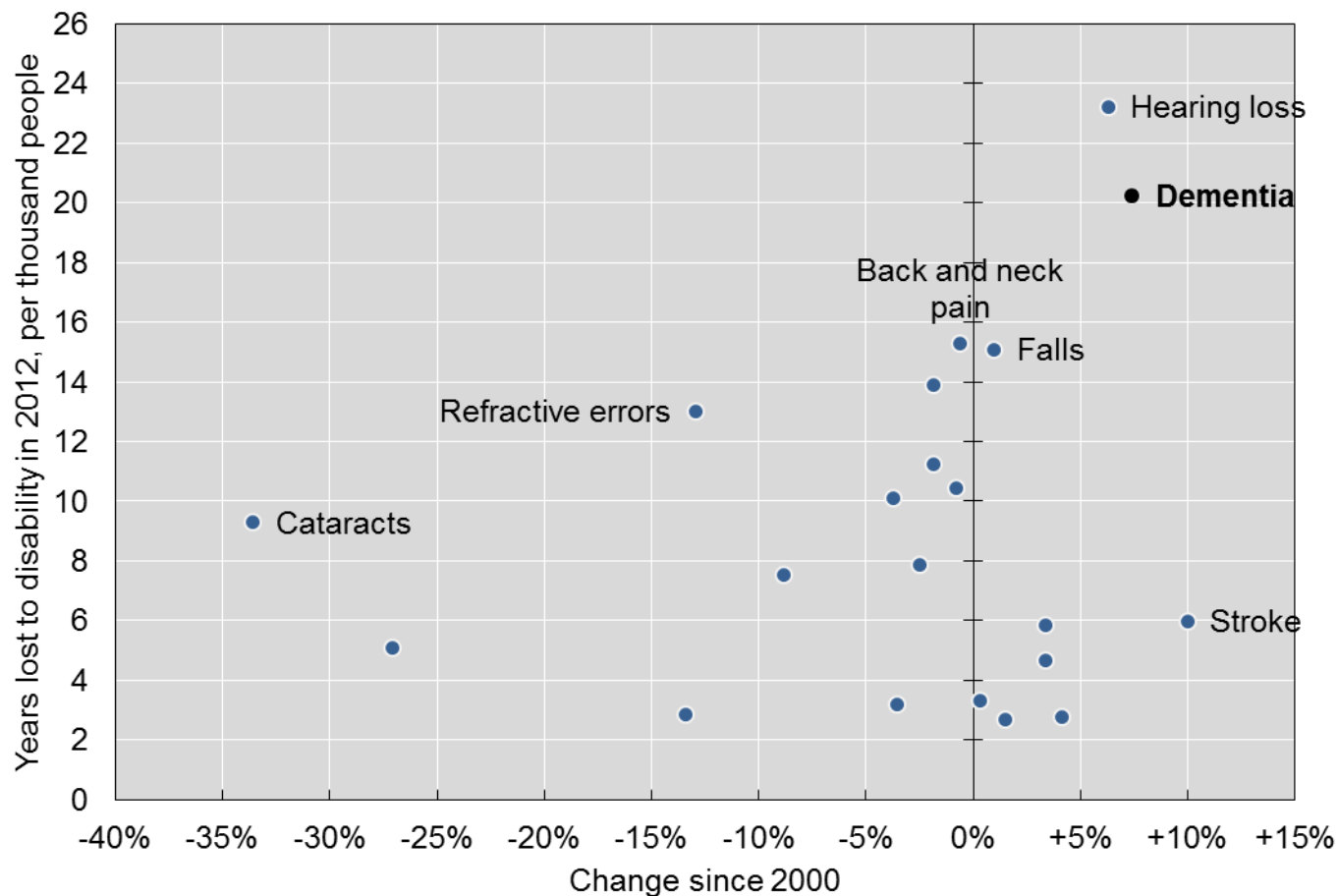
Source: WHO Global Health estimates 2014

* "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



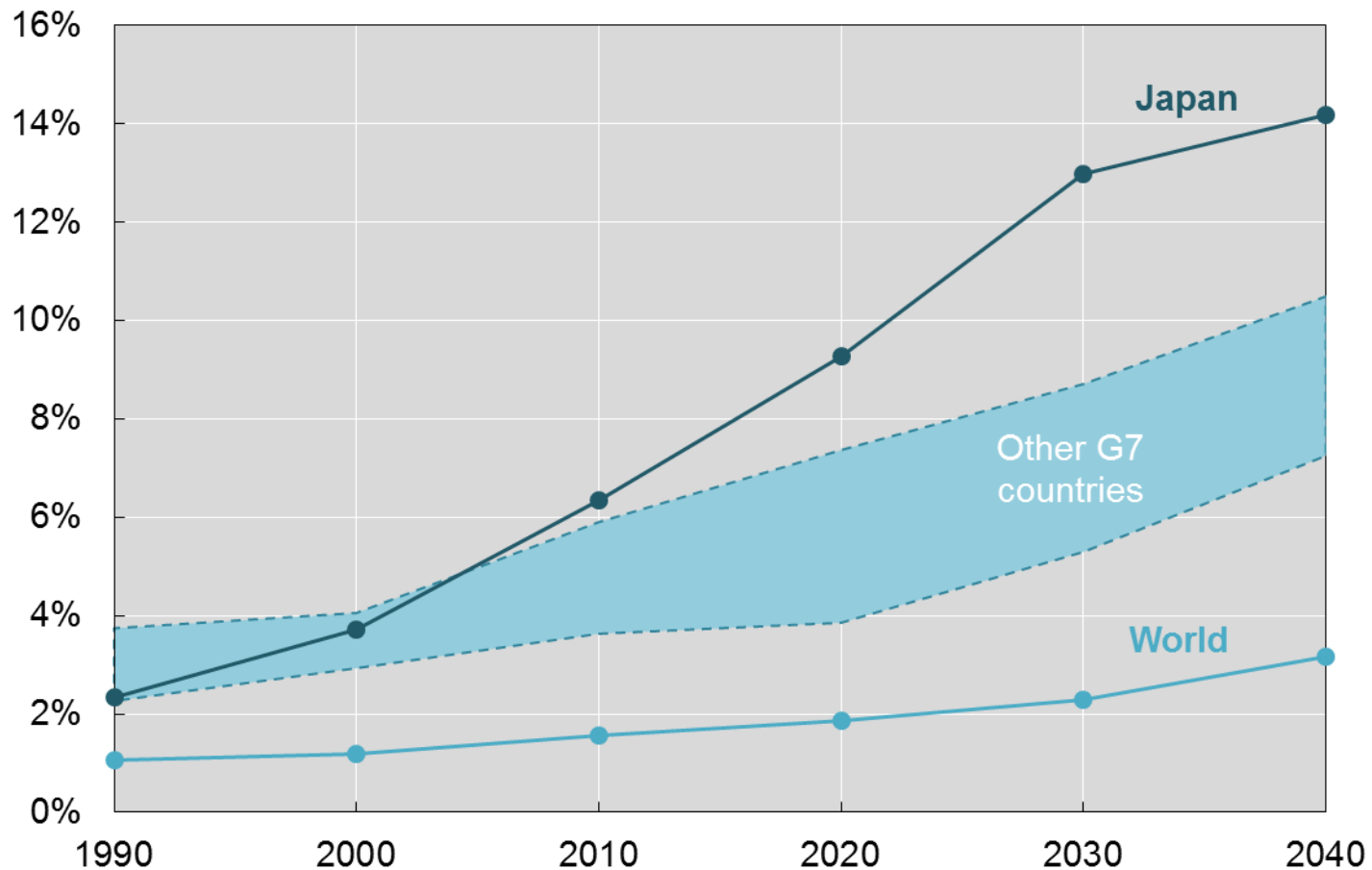
Source: WHO Global Health estimates 2014

* "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...

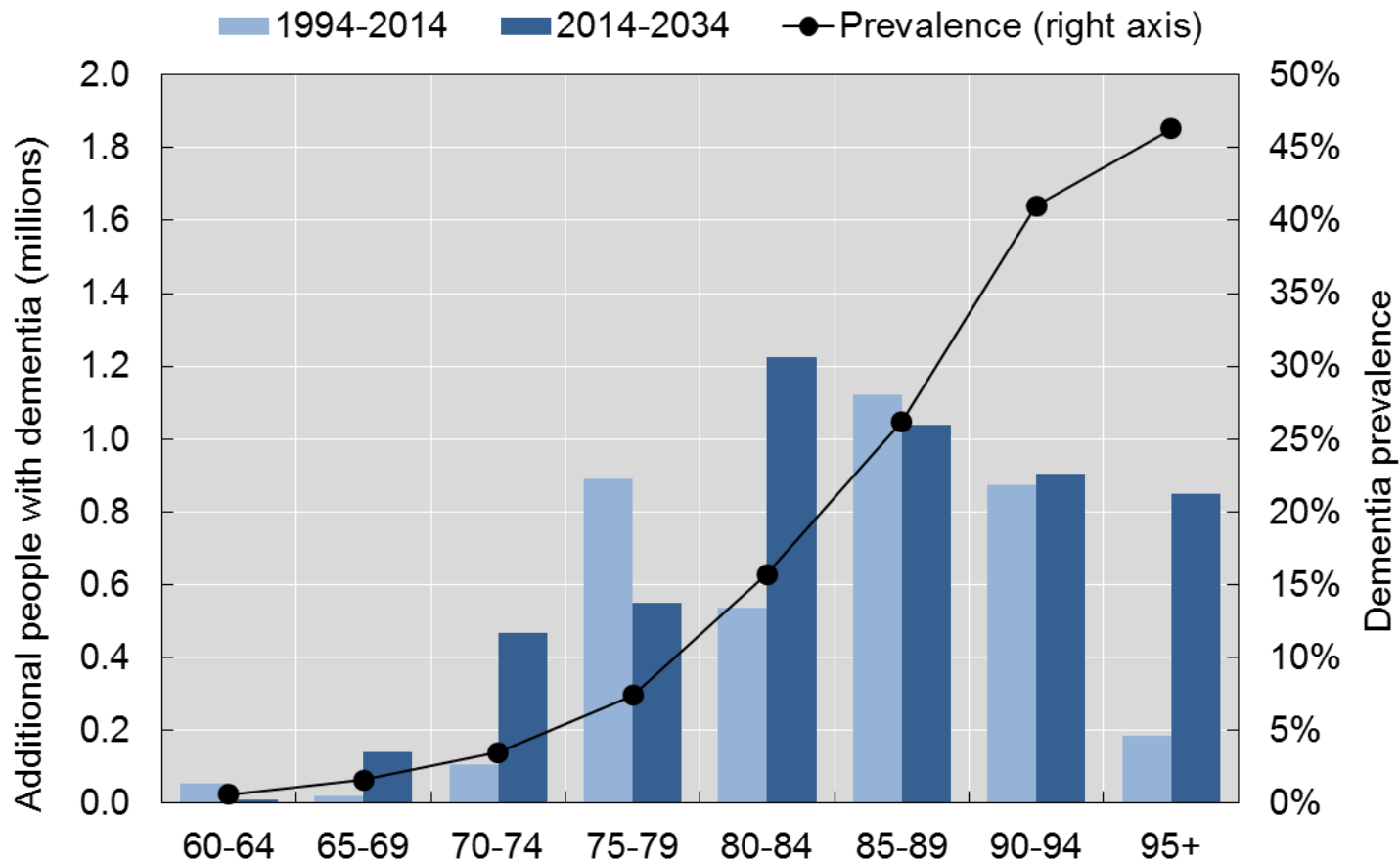
Proportion of the population over 80





...and the fact that dementia prevalence is strongly linked to age.

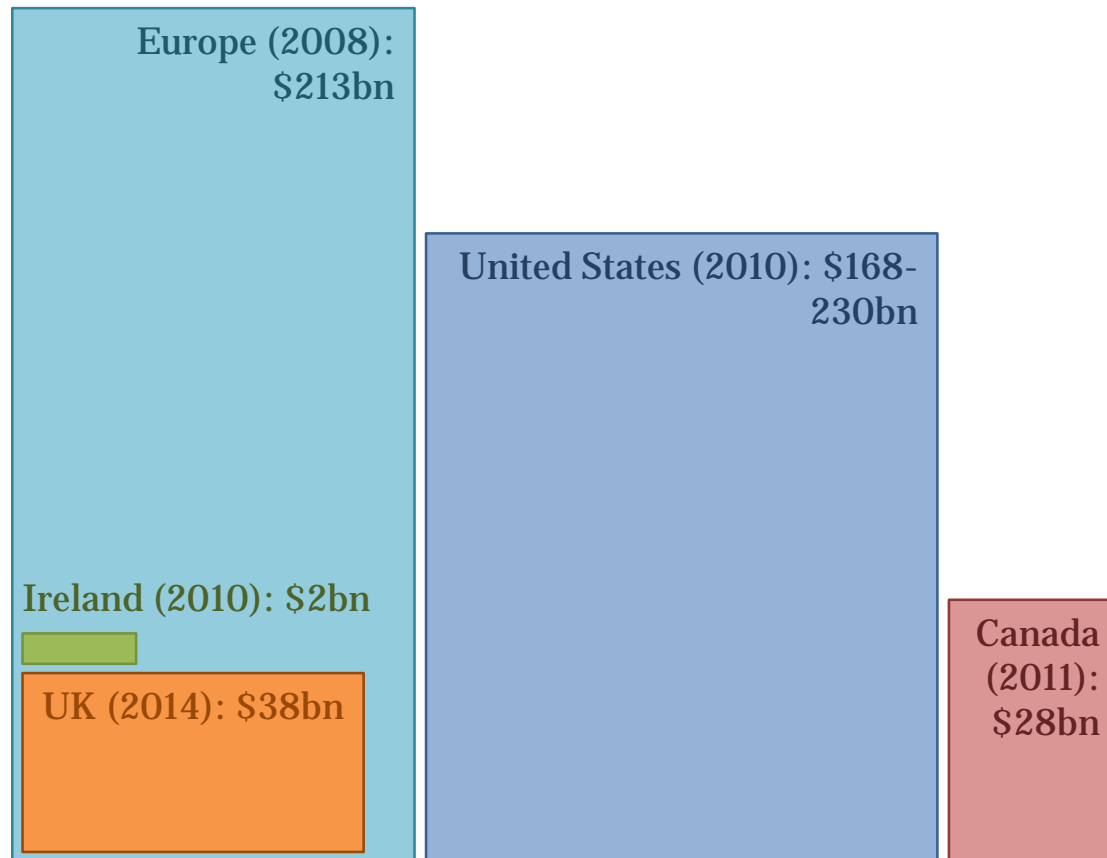
Dementia prevalence in Europe by age and the additional number of people with dementia as a result of ageing in the last 20 and next 20 years





The financial cost of dementia is a major issue globally

Cost of dementia (US\$, 2013 prices)

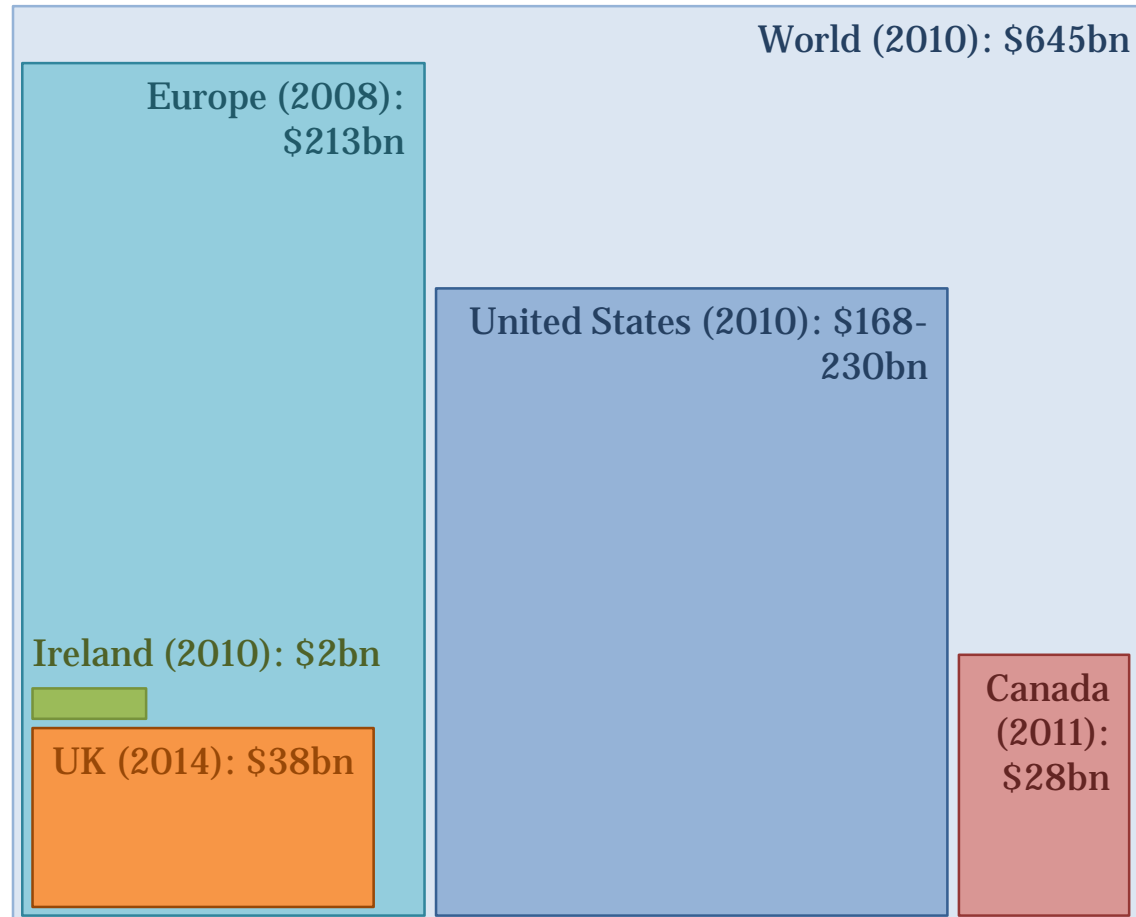


Sources: Wimo, A. et al. (2013); Wimo, A. et al. (2011); Connolly, S. et al. (2014); Prince, M., Knapp, M. et al. (2014); Hurd et al. (2013); Canadian Institutes of Health Research



The financial cost of dementia is a major issue globally

Cost of dementia (US\$, 2013 prices)



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



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

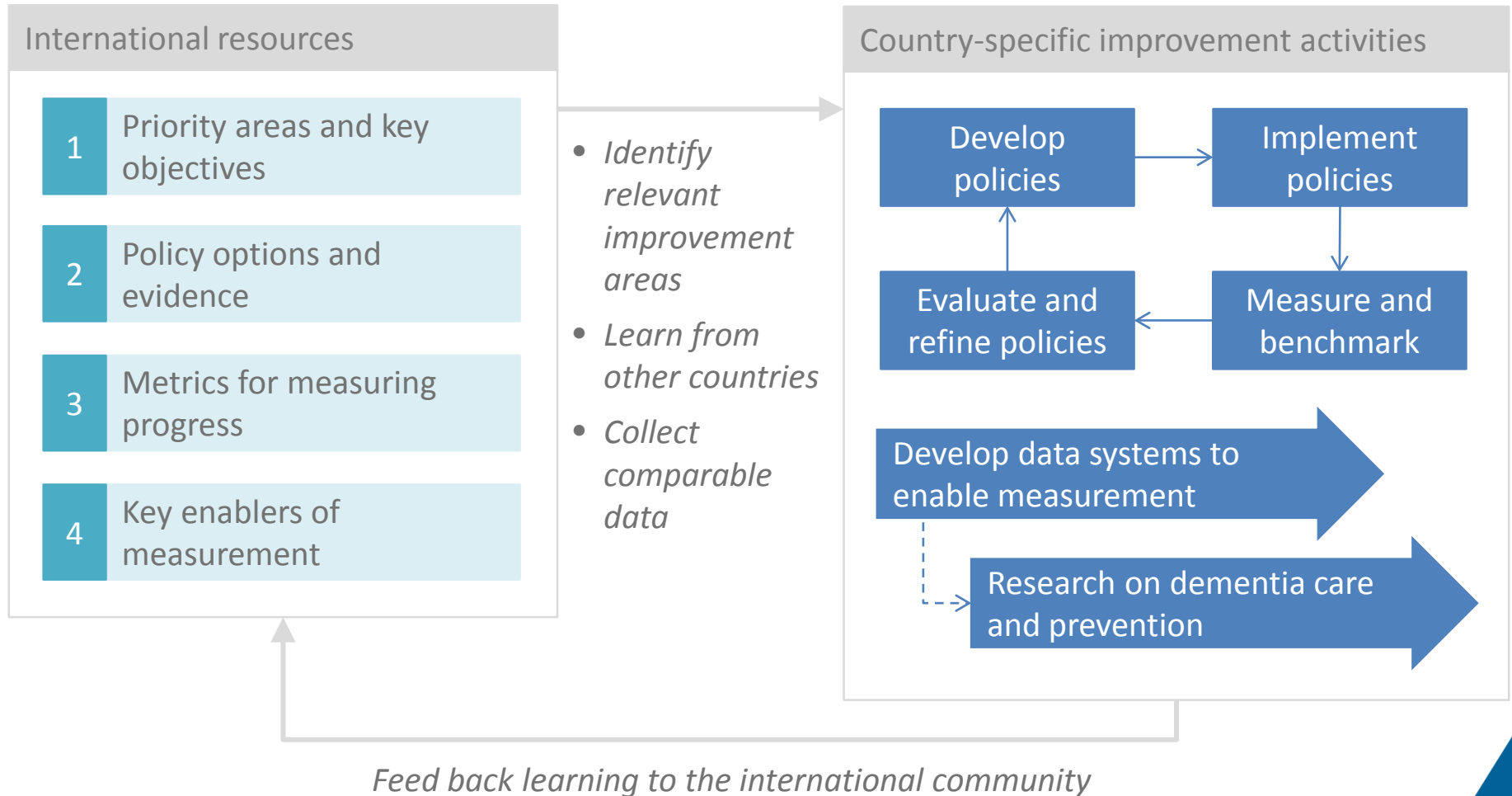
3 Both of these costs are growing



HOW CAN DEMENTIA POLICY BE IMPROVED?

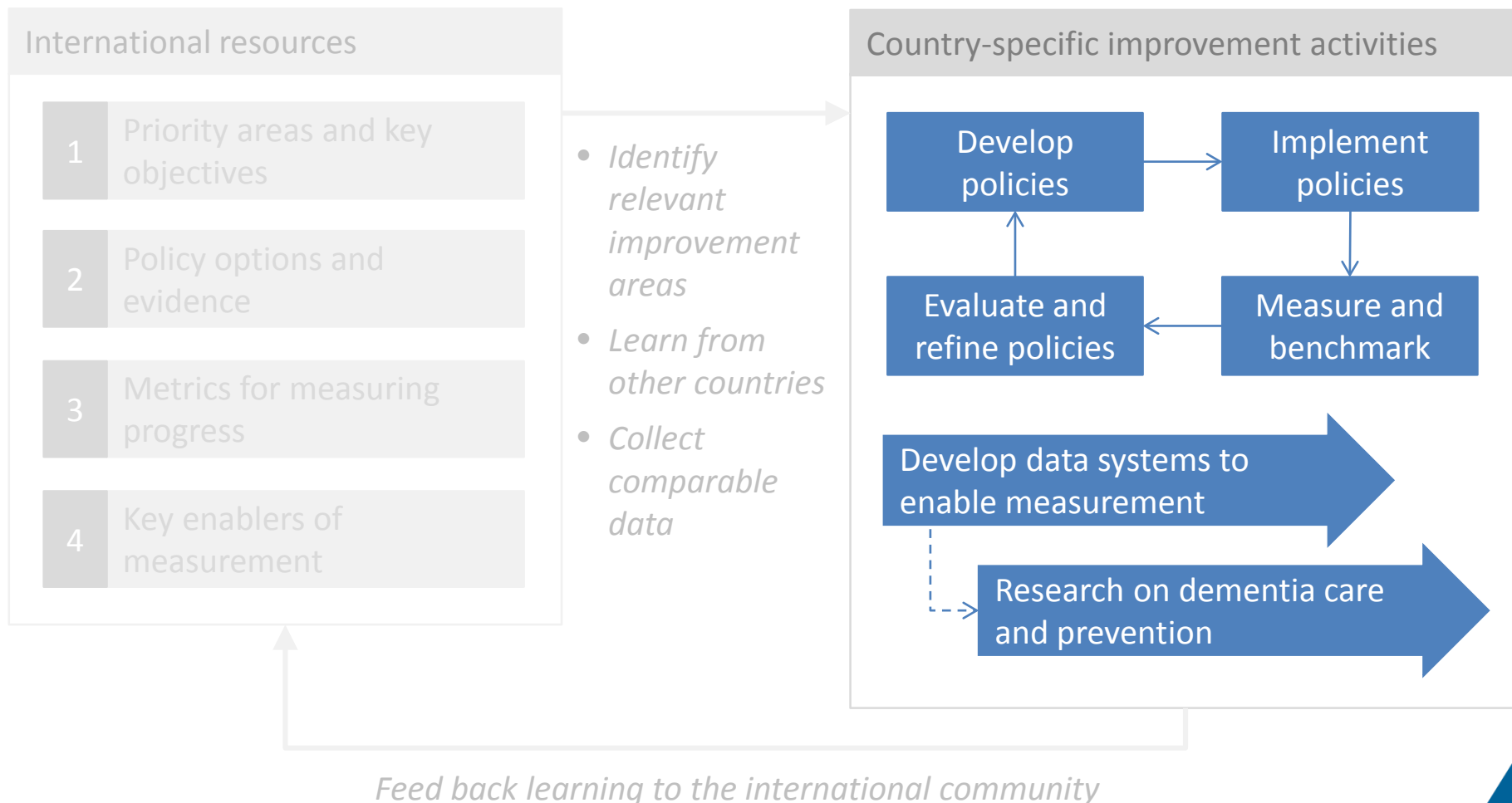


Country strategies should be supported by international collaboration



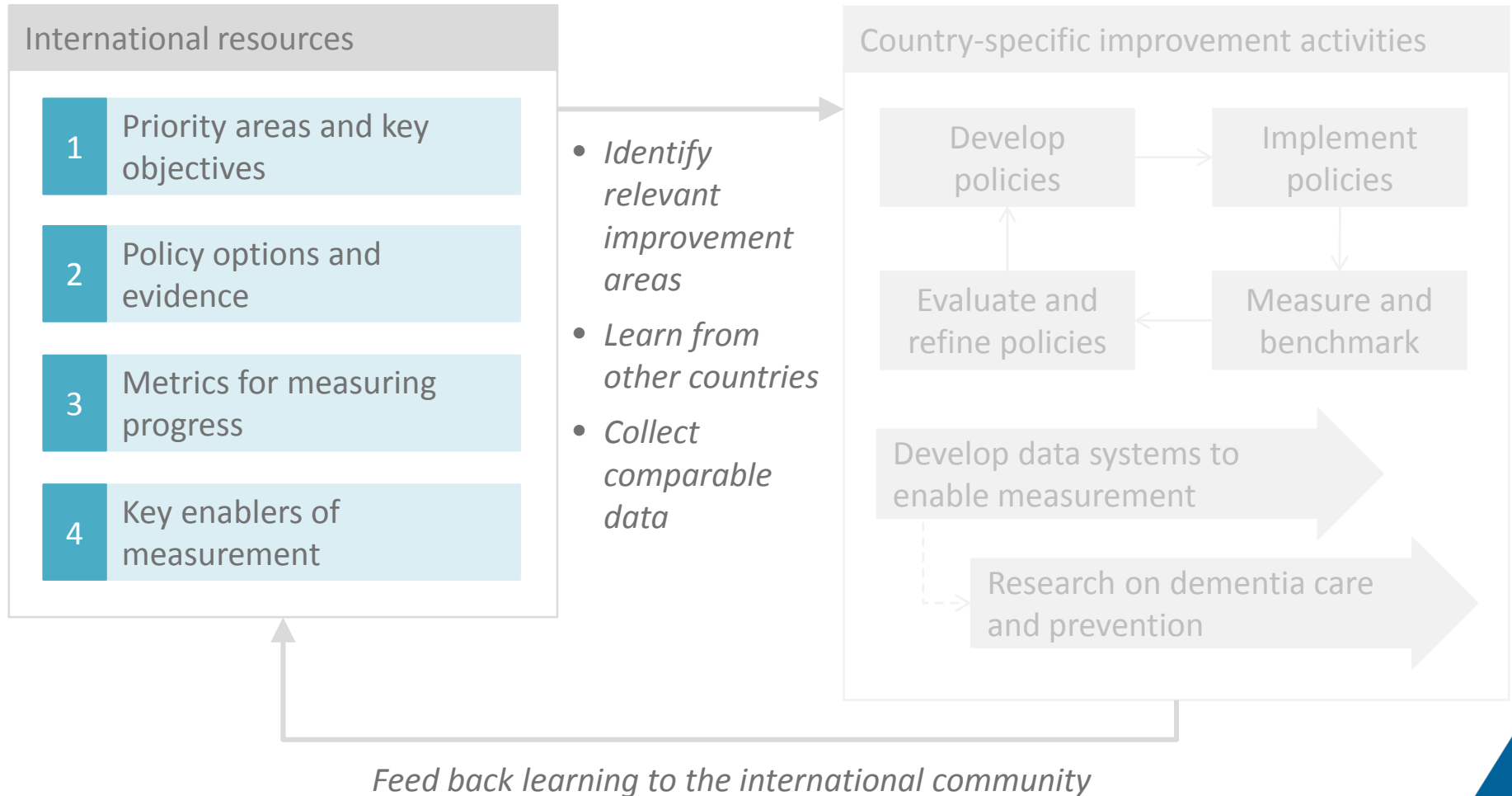


Countries need to focus on evaluating and improving policies



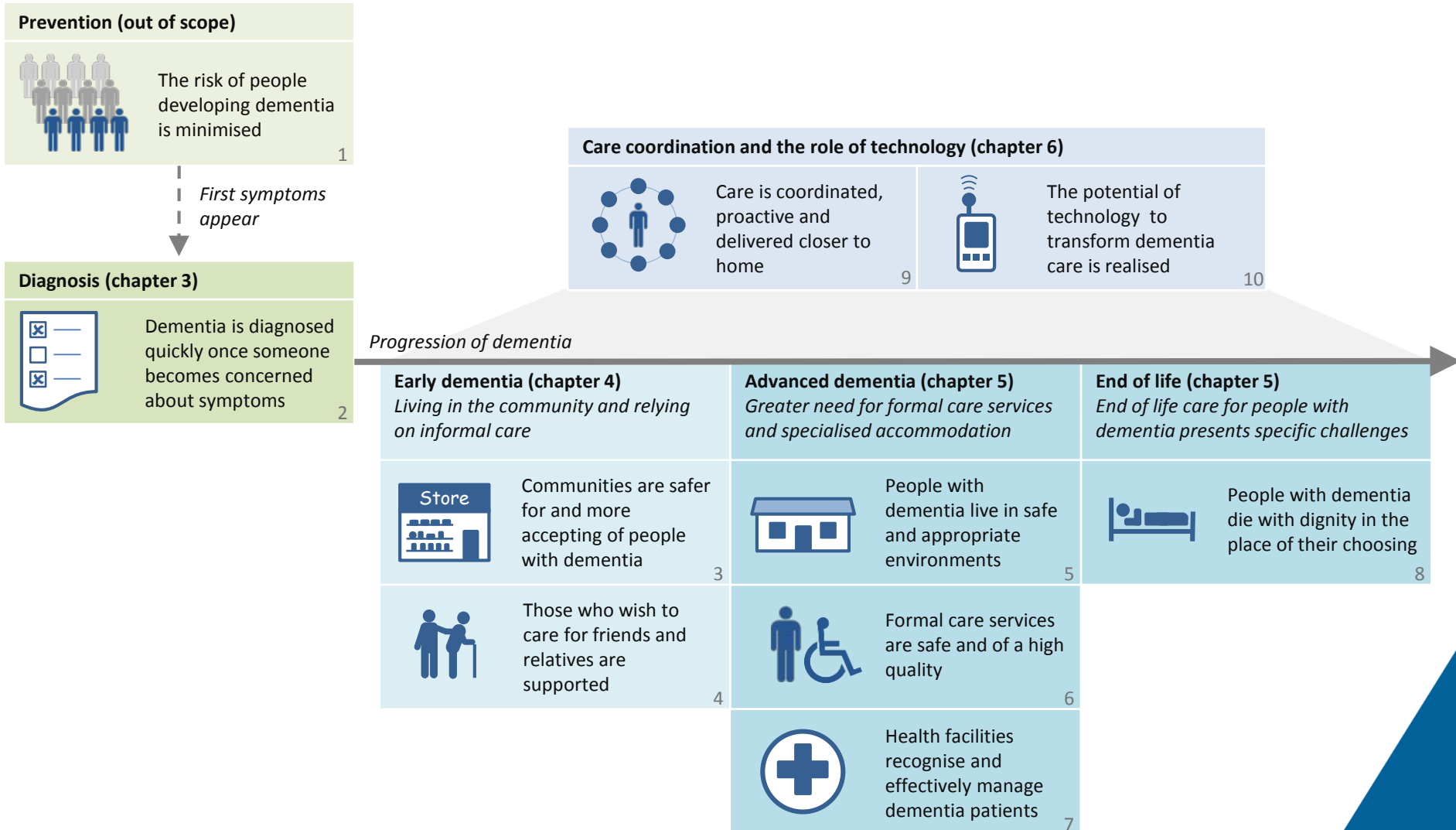


There are four key ways international collaboration can support countries



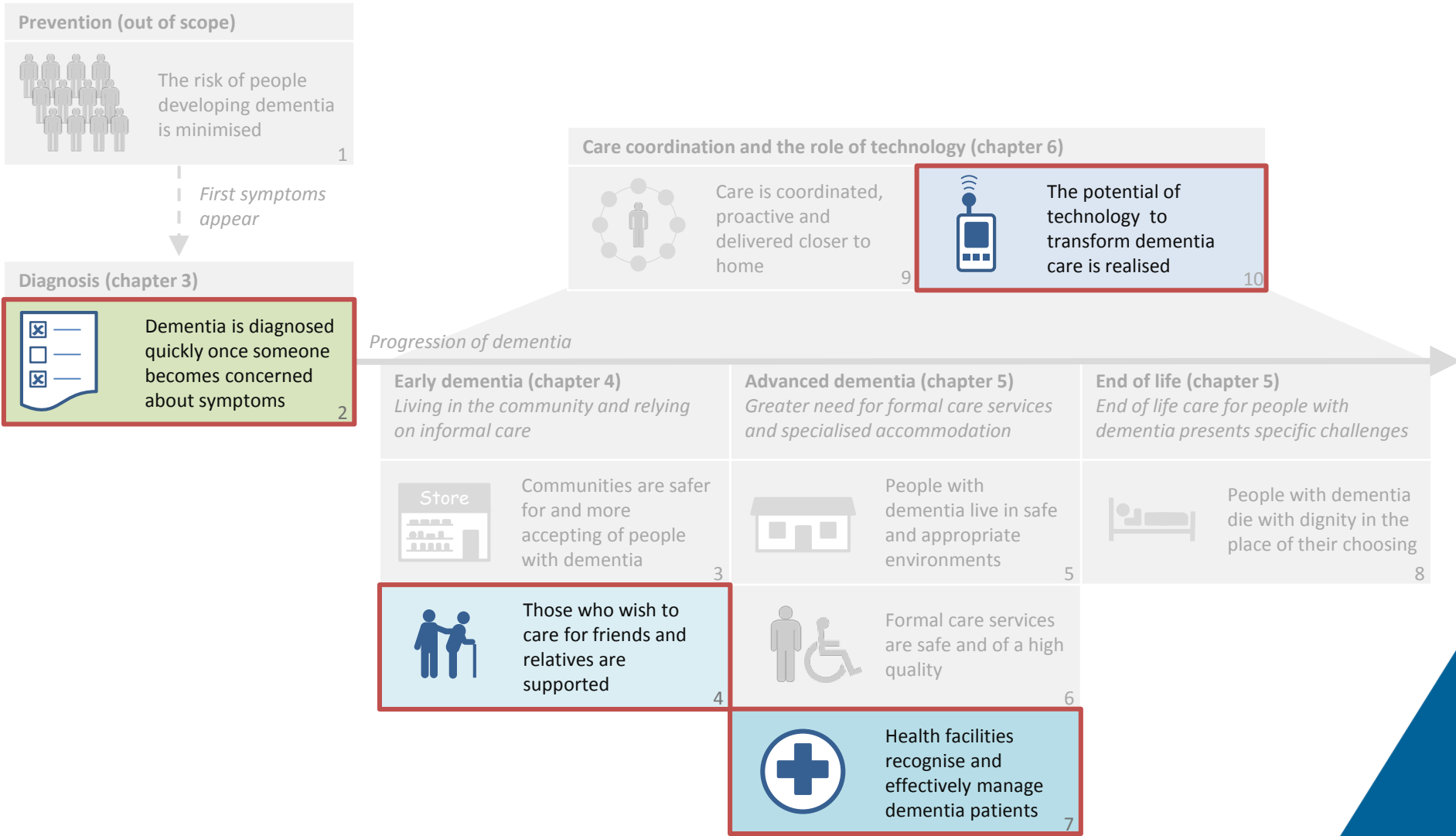


We have identified ten key objectives for dementia policy in OECD countries



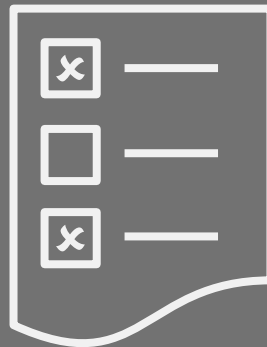


This presentation will focus on four areas where progress is needed





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

Pre-symptomatic stage	Mild symptoms	Advanced dementia
<ul style="list-style-type: none">- Distress- Social stigma- Risk of over-diagnosis	<ul style="list-style-type: none">+ Can reduce anxiety if someone is concerned about symptoms+ Able to plan- Distress or social stigma- Risk of over-diagnosis	<ul style="list-style-type: none">+ Access to services+ Management of risks (e.g. in hospital)+ Able to plan (incl. end-of-life care)
Currently no case for pre-symptomatic screening	Those concerned about symptoms should be diagnosed	All cases of advanced dementia should be diagnosed



Diagnosis should be available to those who are concerned about symptoms

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

Pre-symptomatic stage	Mild symptoms	Advanced dementia
<ul style="list-style-type: none">- Distress- Social stigma- Risk of over-diagnosis	<ul style="list-style-type: none">+ Can reduce anxiety if someone is concerned about symptoms+ Able to plan- Distress or social stigma- Risk of over-diagnosis	<ul style="list-style-type: none">+ Access to services+ Management of risks (e.g. in hospital)+ Able to plan (incl. end-of-life care)
Currently no case for pre-symptomatic screening	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



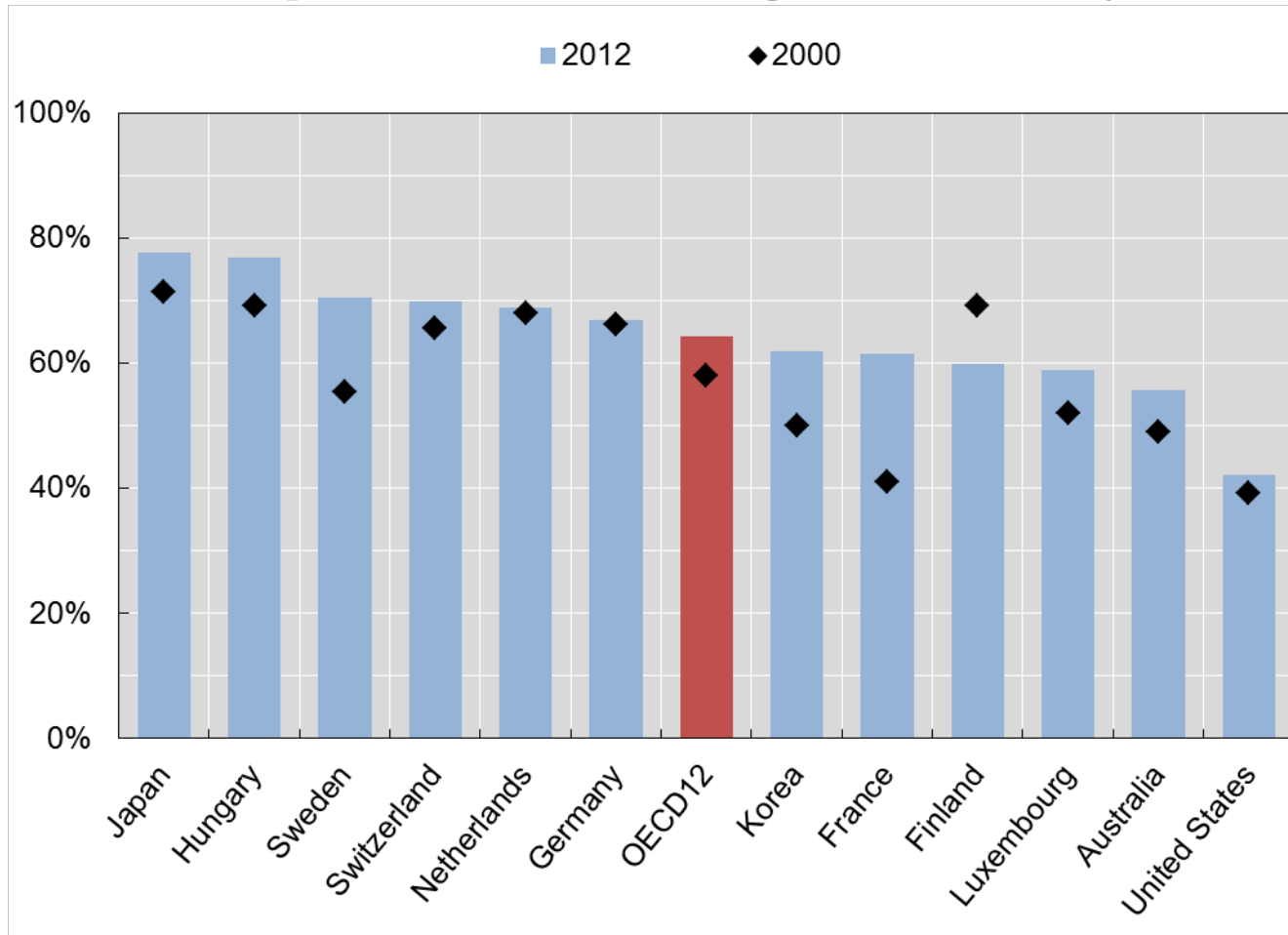
SUPPORTING INFORMAL CARERS





Most OECD countries are moving towards more community care...

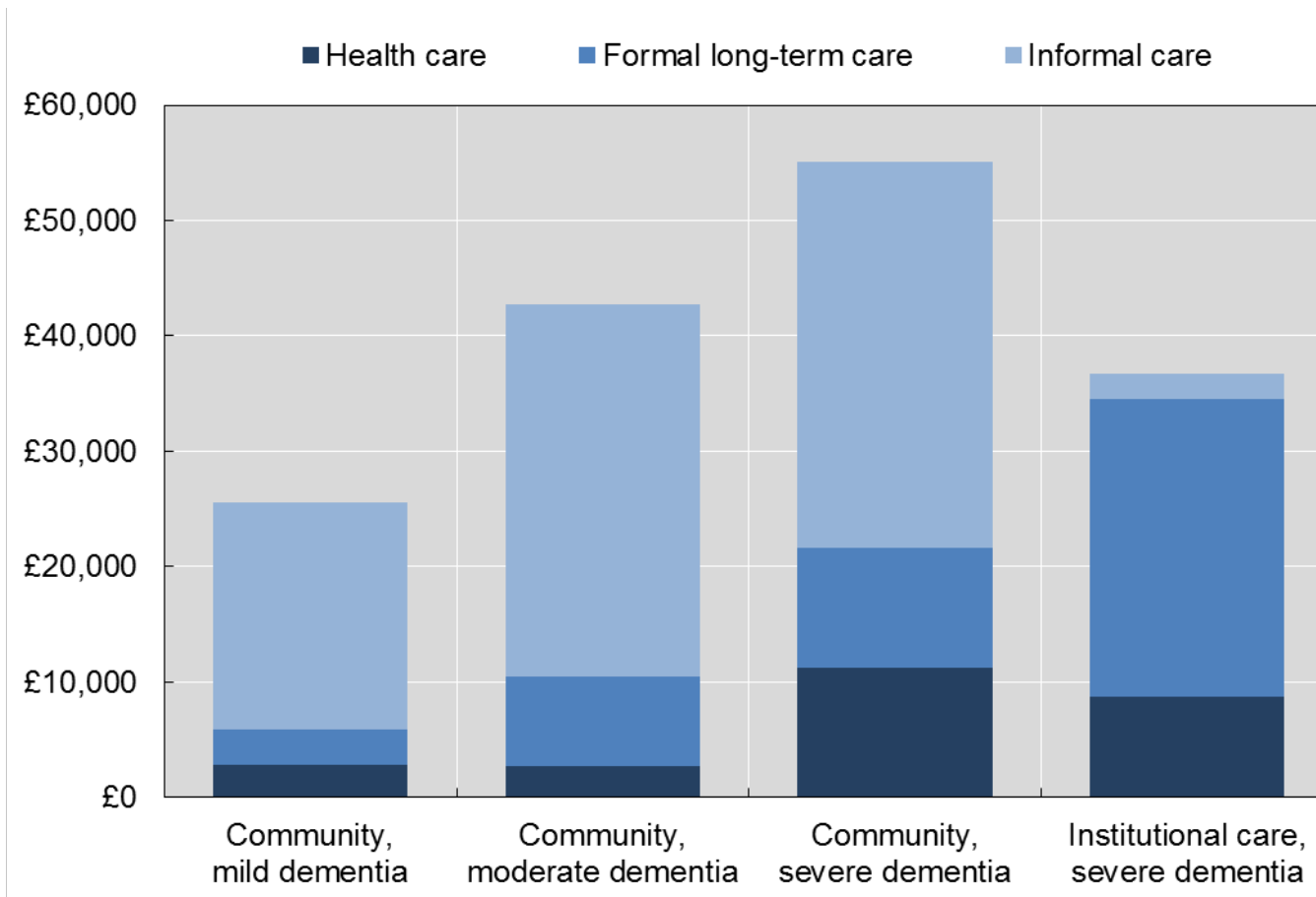
Proportion of LTC users living in the community





...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



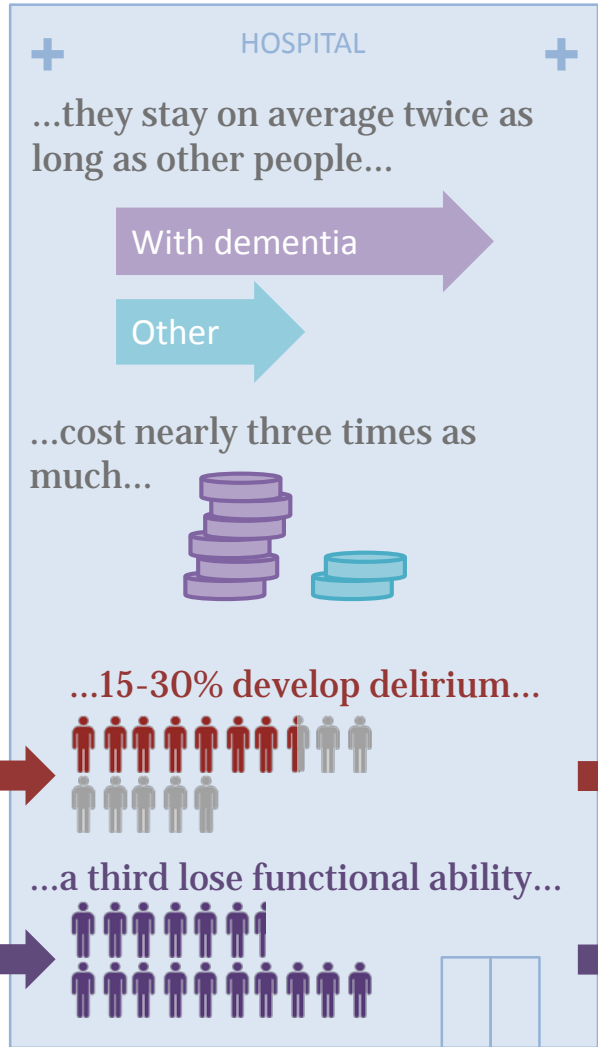
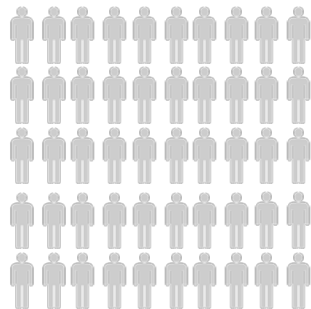
MANAGING DEMENTIA IN HOSPITALS





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...

With dementia
Other

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

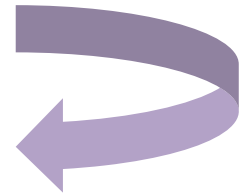
...15-30% develop delirium...



...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.





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

Information sharing can identify existing diagnoses

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



Providing appropriate care

Managing risks such as delirium, distress and pressure ulcers

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



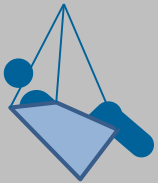
Promoting social interaction

- e.g. Paro robot in **Japan**
- Randomised clinical trial planned in the Netherlands



Managing medical needs

- Automated dispensers to reduce medication error (e.g. **Germany**)
- *Telehomecare nurses* in **Canada** provide remote support



Mechanical lifting devices

- Reduce manual lifting and the risk of injury
- **British Columbia (Canada)** aims to eliminate manual lifting



Monitoring systems

- *ComfortZone* in the **United States** provides tracking devices
- The *Independent Project* in **Europe** is piloting alarms, fall detectors and gas detectors.



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 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

Read more about our work



Follow us on Twitter: [@OECD_Social](https://twitter.com/OECD_Social)



Website: www.oecd.org/health