

Quality of life and quality of care in dementia: reasons to be cheerful

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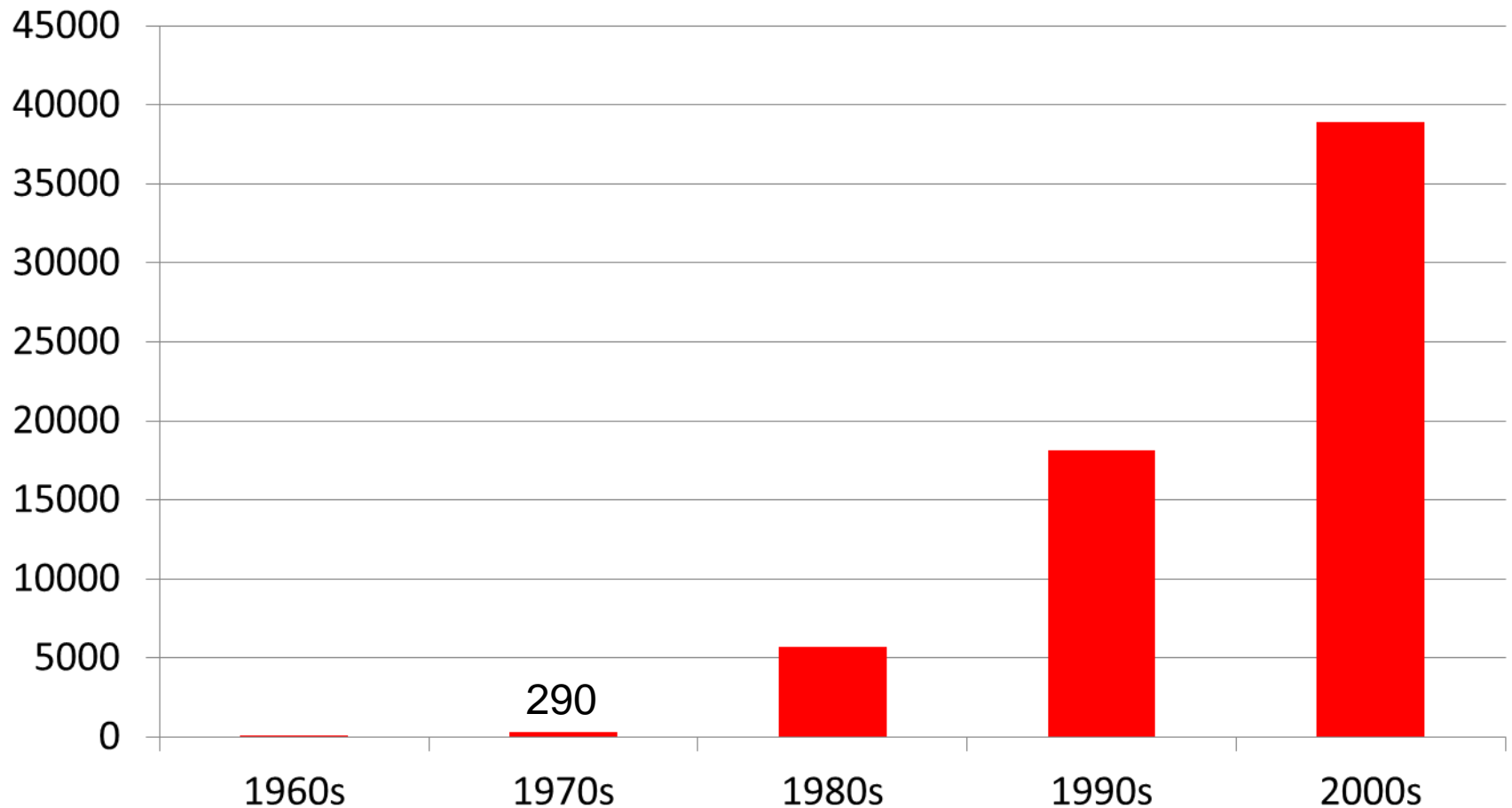
Sussex Partnership NHS Foundation Trust



Reasons to be cheerful part 1

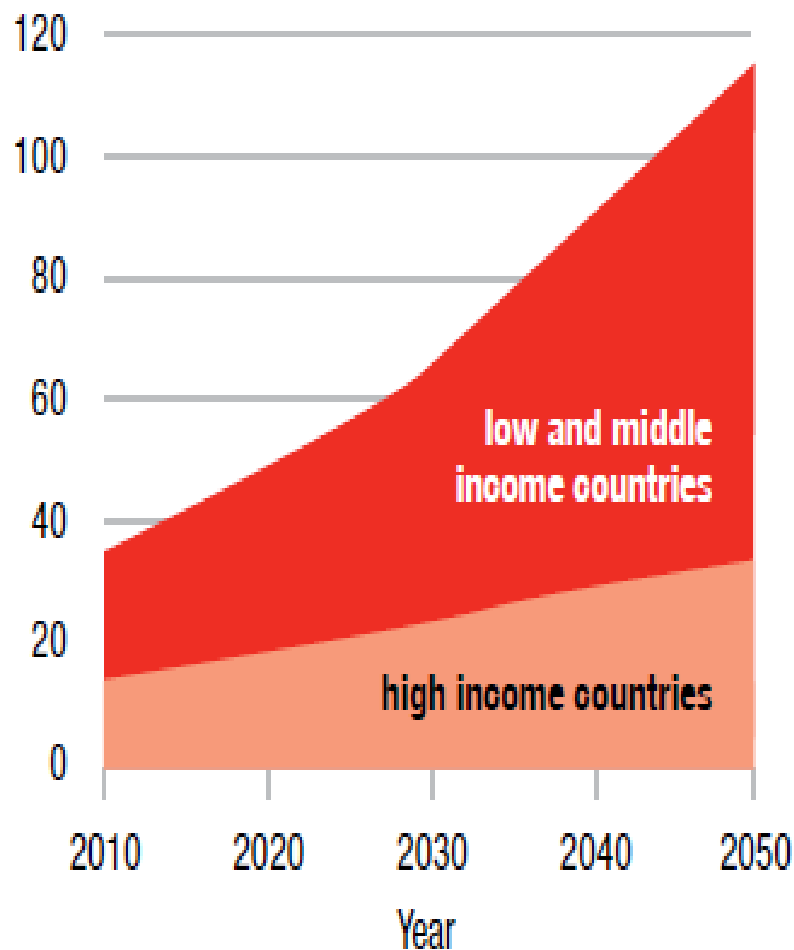
**WE KNOW MUCH MORE ABOUT
DEMENTIA**

Numbers of papers on Alzheimer's Disease by decade



Growth of numbers of people with dementia

Numbers of people with dementia (millions)



- **The World Alzheimer Report (2009) estimated:**
 - 35.6 million people living with dementia worldwide in 2010
 - Increasing to 65.7 million by 2030
 - 115.4 million by 2050

Future projections

The number of people in the UK with dementia will double in the next 40 years.

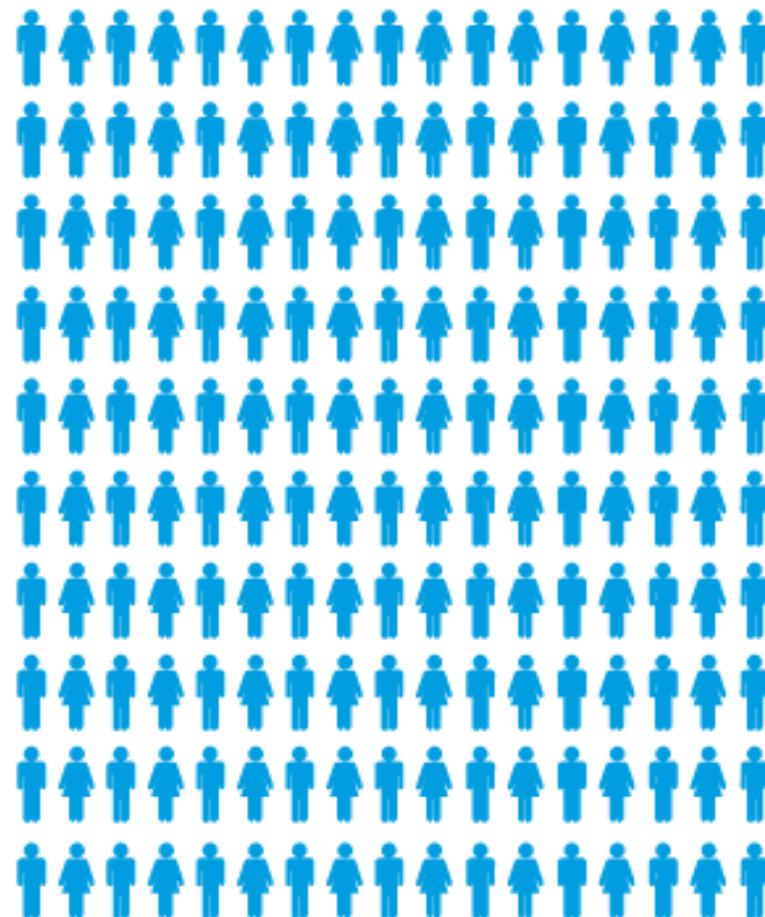
 = 10,000 people



80,000 people
with dementia in
2012

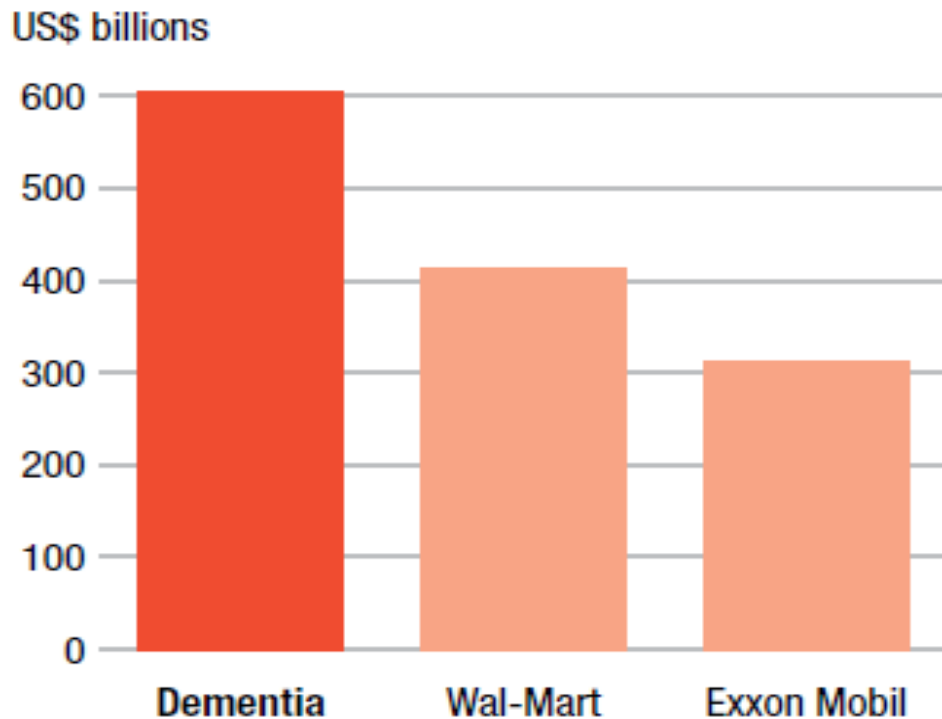


1,000,000 people
with dementia in
2021



1,700,000 people
with dementia in
2051

Worldwide cost of dementia

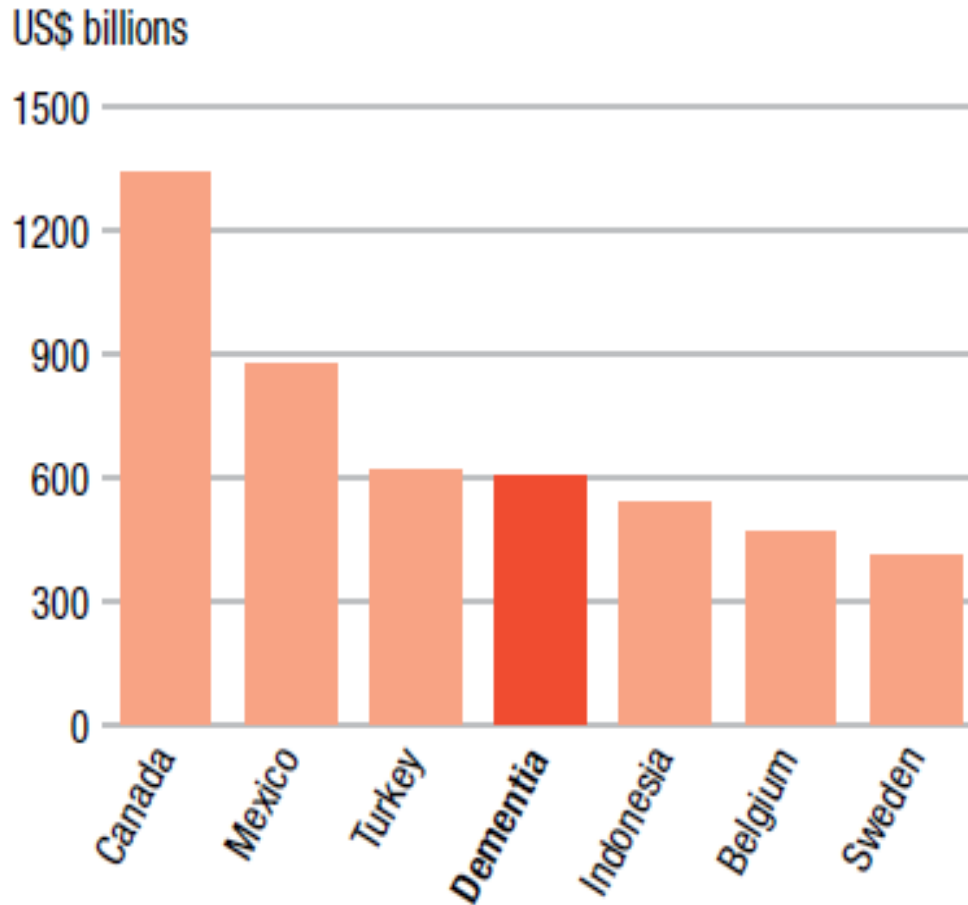


- The societal cost of dementia is already enormous.
- Dementia is already significantly affecting every health and social care system in the world.
- The economic impact on families is insufficiently appreciated.
- The total estimated worldwide costs of dementia are US\$604 billion in 2010.
- These costs are around 1% of the world's GDP

0.24% in low income

1.24% in high income

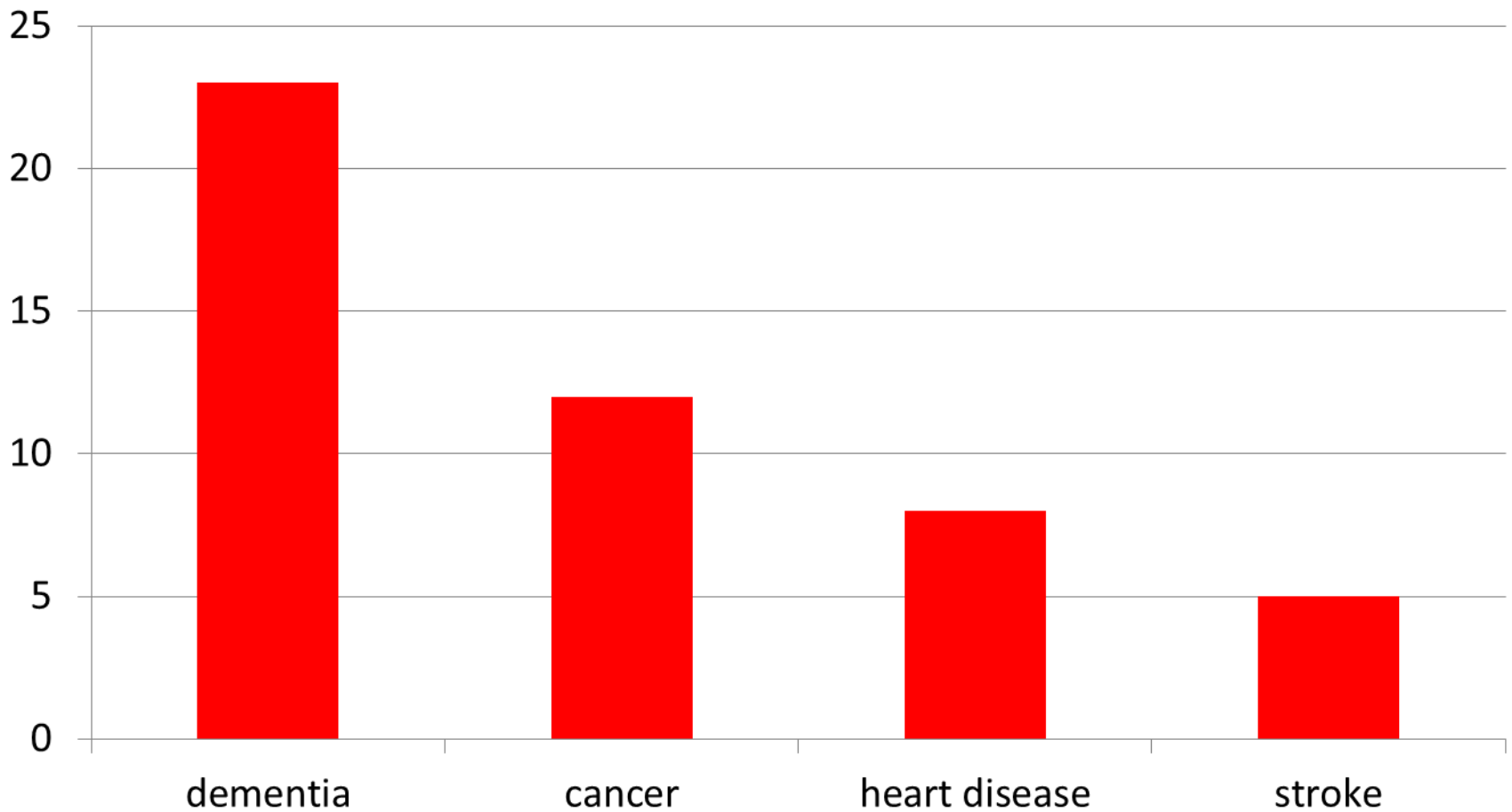
Worldwide costs of dementia



- The World Alzheimer Report (2010) estimated that:

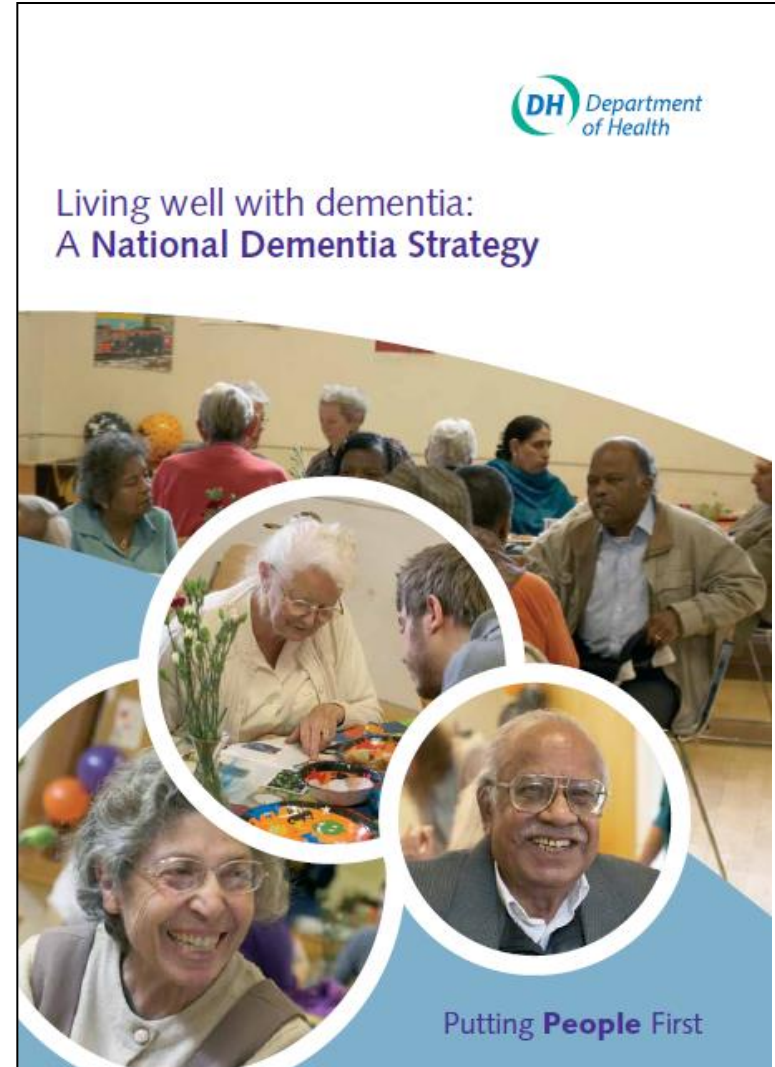
If dementia care were a country, it would be the world's 18th largest economy

Cost of illness per year (£billion)



National dementia strategies

- France
- Wales
- Scotland
- Australia
- Germany
- Japan
- South Korea
- India
- England 2009



Change the word – Japan, we need to change the beliefs

Chihō

痴

Idiocy

呆

Stupidity



Ninchishō

認知

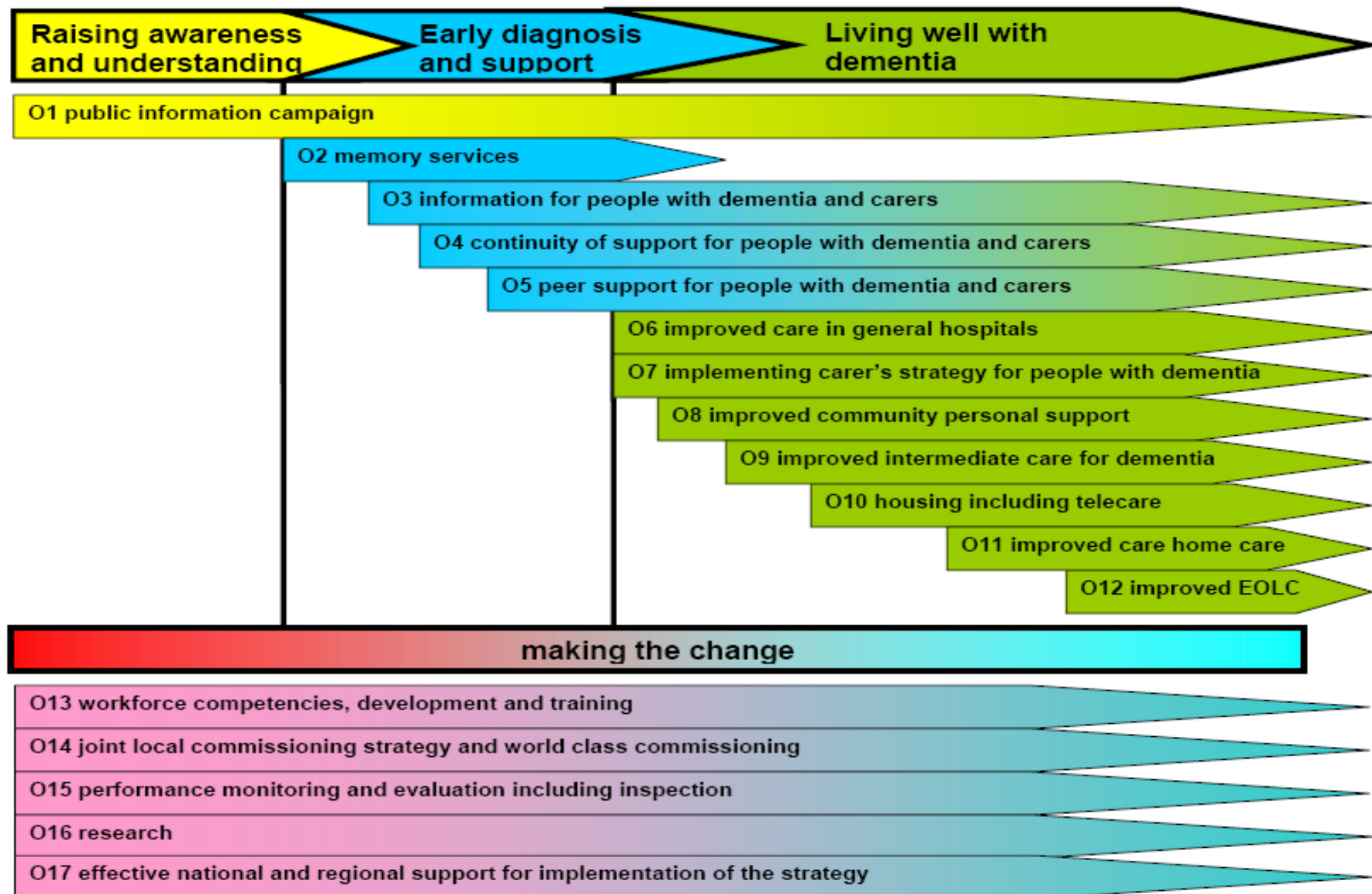
Cognition

症

Disorder

In 2004, the Japanese Government modified the Japanese terminology for "Dementia"

Objectives of the National Dementia Strategy



WHO Report, 2012

- Prevalence
- Numbers
- New incidence data
- Cost
- Policy



M. Chan

Dr. Margaret
Chan, Director
General, WHO

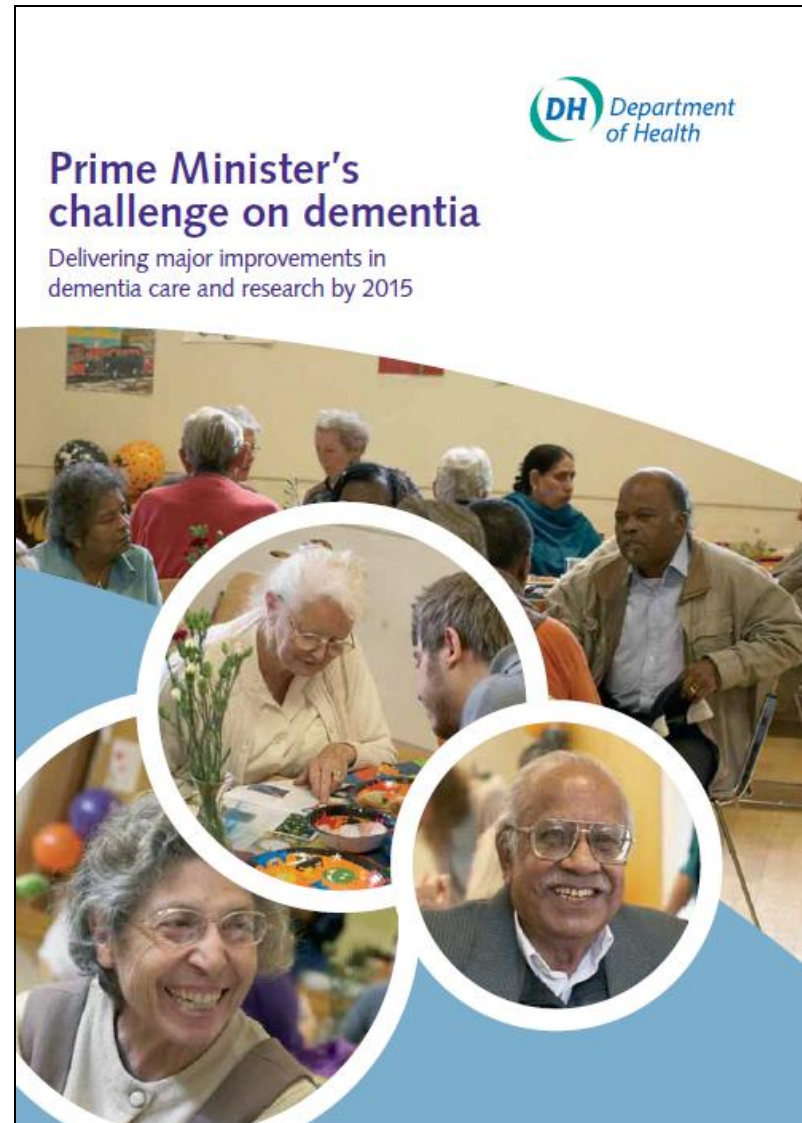
“I call upon all stakeholders to make health and social care systems informed and responsive to this impending threat”



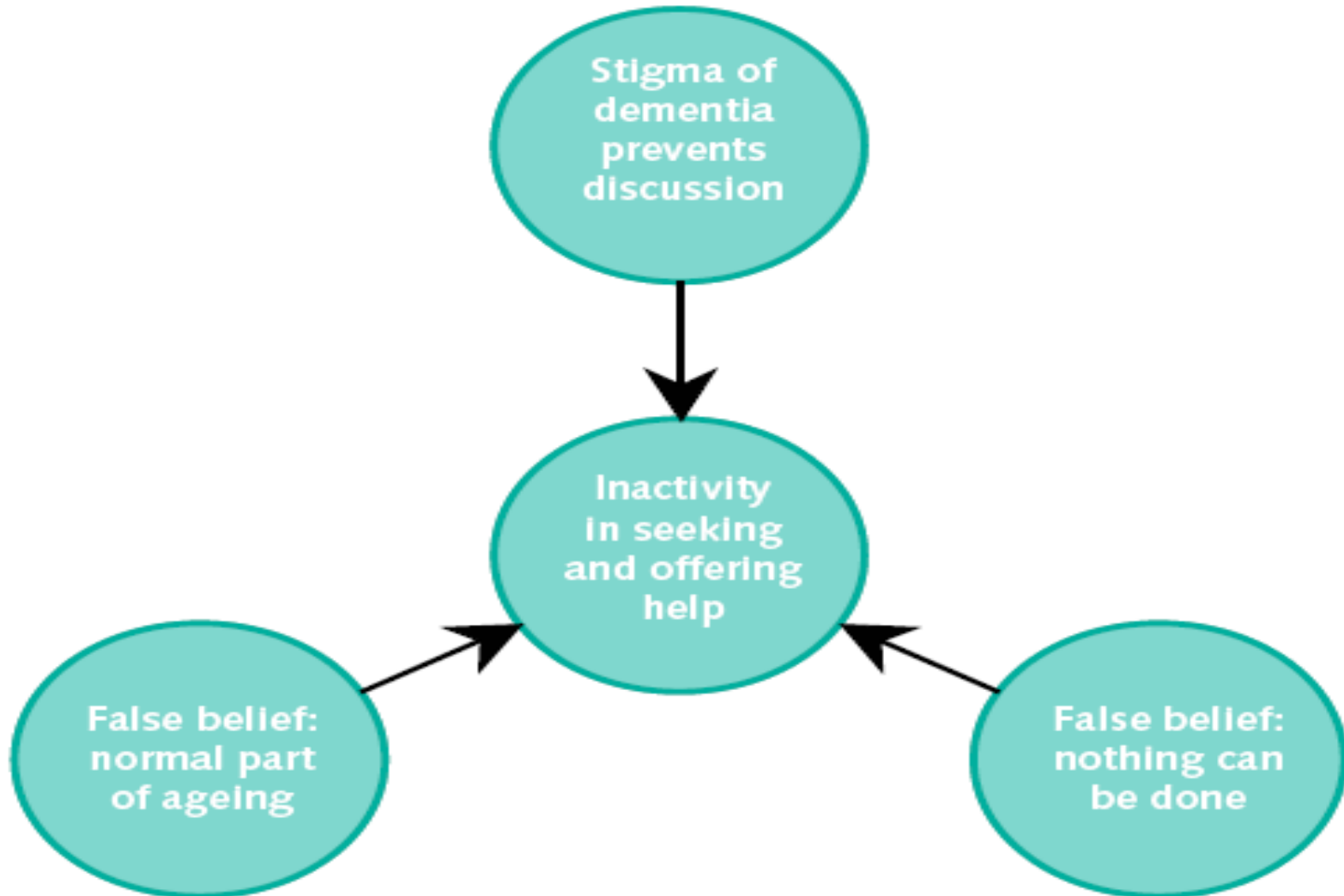
DEMENTIA A PUBLIC HEALTH PRIORITY

PM Challenge and G8 Dementia Summit

“So I am determined that we will go further and faster on dementia – making life better for people with dementia and their carers, and supporting the research that will ultimately help us slow, stop and even prevent the condition”



Dismantling the barriers to care: public and professional attitudes and understanding



Health promotion, education



**Worried
someone
close
to you
is losing
their
memory?**

Many people suffer from memory loss as they get older. But if it starts to happen on a regular basis, it could be the early signs of dementia.

If you're worried, see your doctor

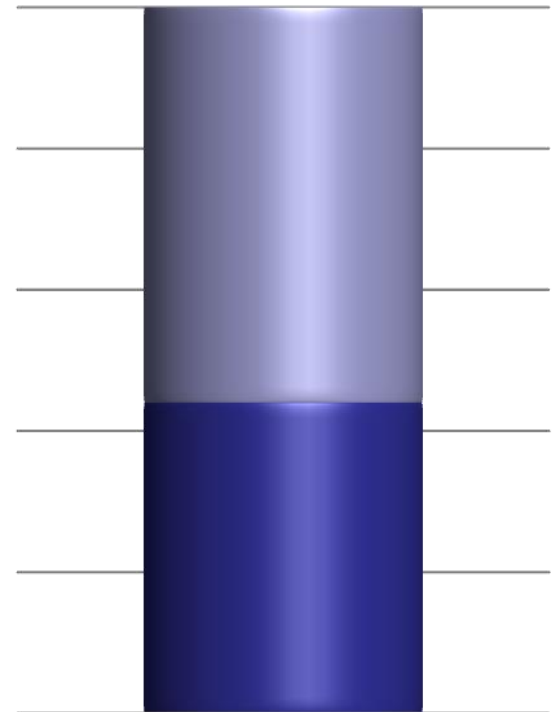


Reasons to be cheerful part 2

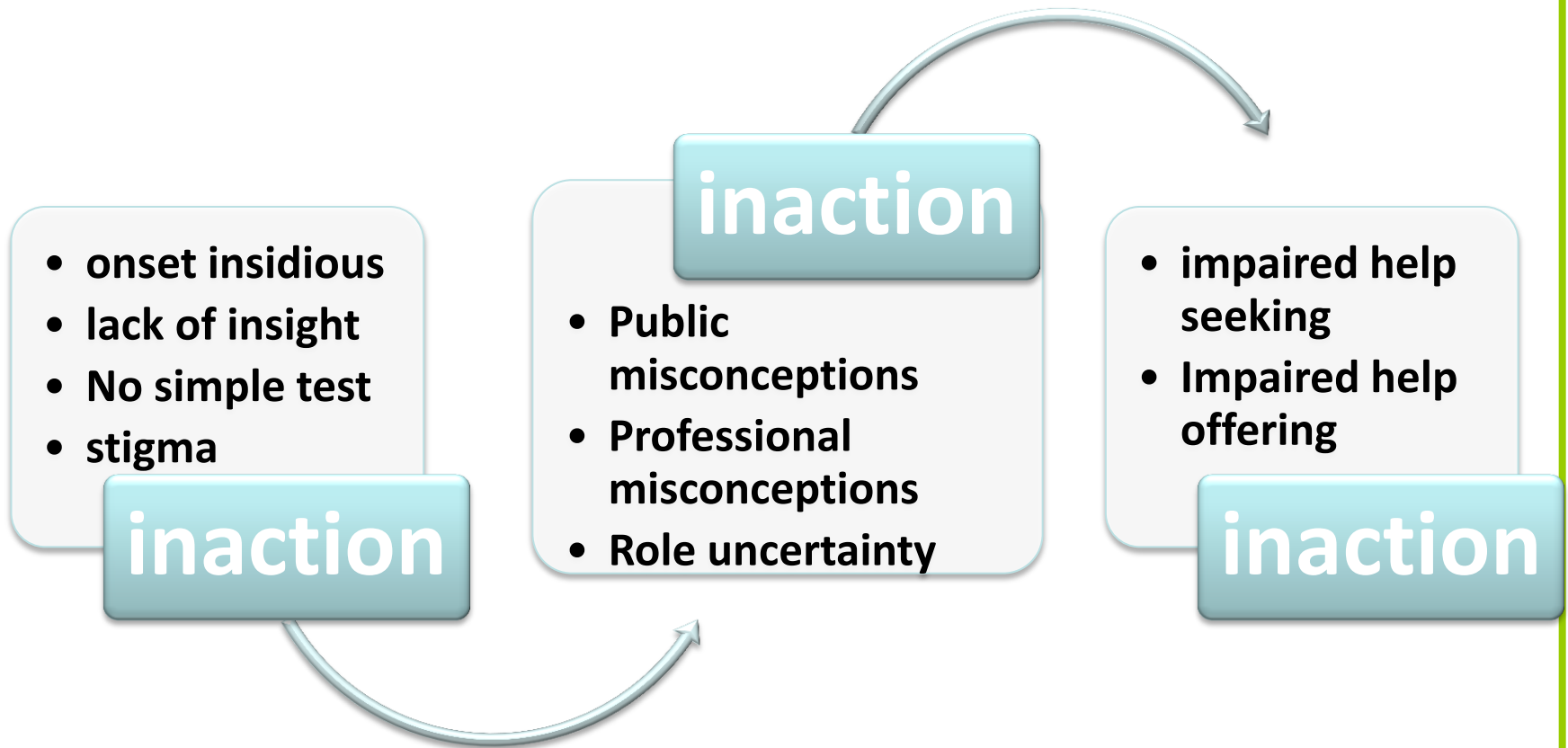
BETTER DIAGNOSIS OF DEMENTIA

The fundamental problem - now

- Only around 44% of people with dementia receive any specialist health care assessment or diagnosis
- When they do, it is:
 - Late in the illness
 - Too late to enable choice
 - At a time of crisis
 - Too late to prevent harm and crises

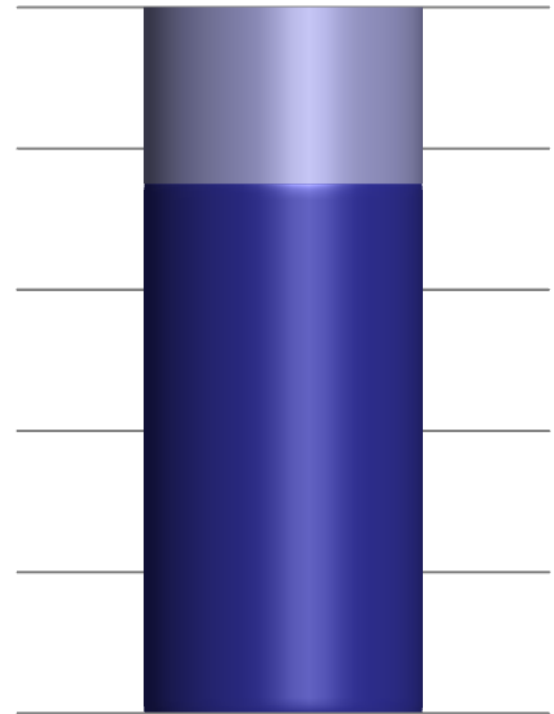
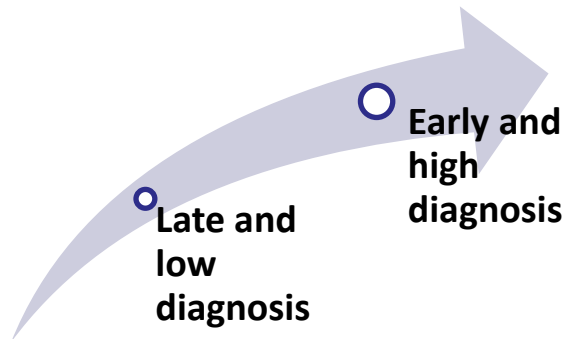


Why inaction?



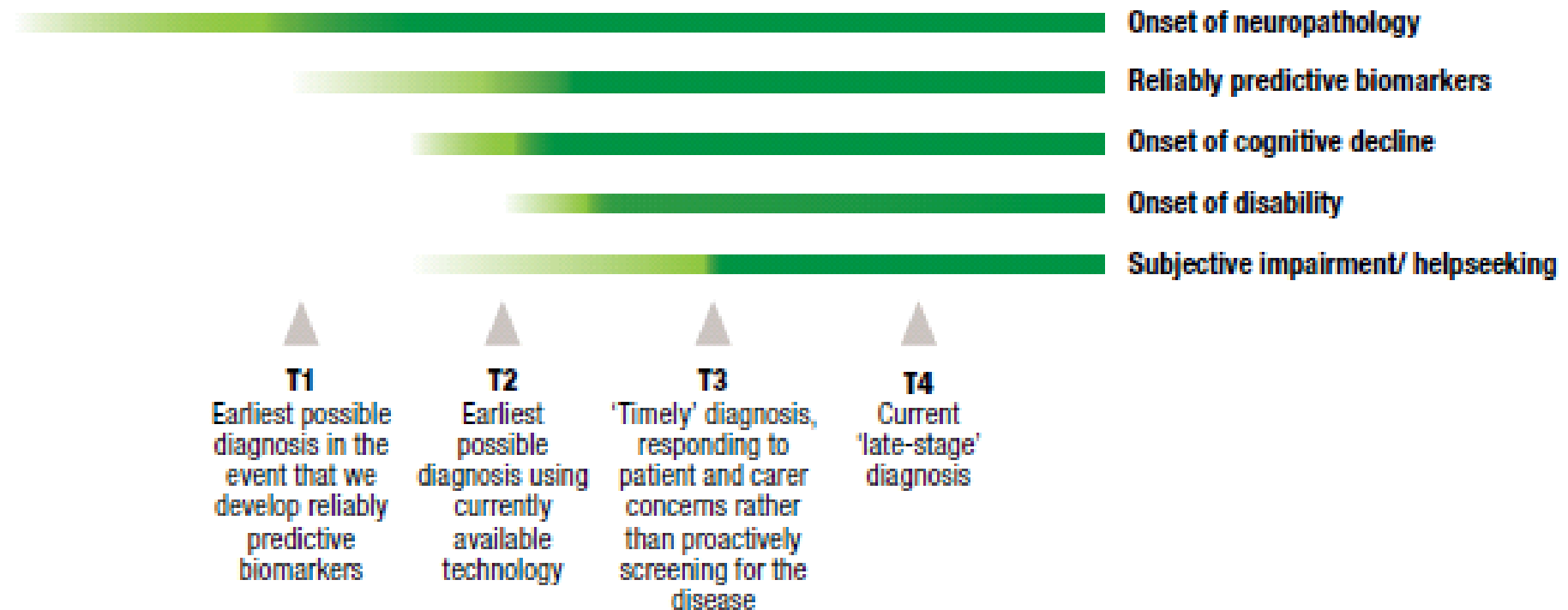
The goal

- 70-80% of people with dementia receive accurate assessment and diagnosis
- When they do, it is:
 - Early in the illness
 - Early enough to enable choice
 - In time to prevent harm
 - In time to prevent crises



What do we mean by early diagnosis?

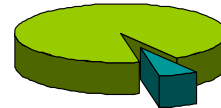
Figure 1: Timeline of disease progression



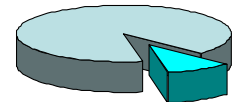
Services for early diagnosis and intervention in dementia for all – markers of quality

- Working for the whole population of people with dementia
 - ie has the capacity to see all new cases of dementia in their population
- Working in a way that is complementary to existing services
 - About doing work that is not being done by anybody
- Service content
 - Make diagnosis well
 - Communicate diagnosis well
 - Provide immediate support and care immediately from diagnosis

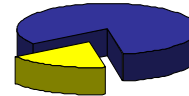
95% acceptance rate



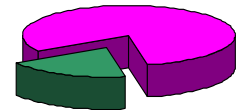
94% appropriate referrals



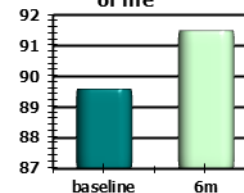
18% minority ethnic groups



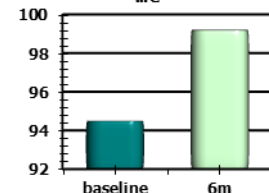
19% under 65 years of age



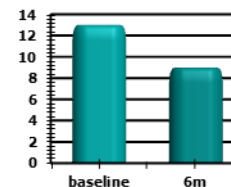
Improvement in self-rated quality of life



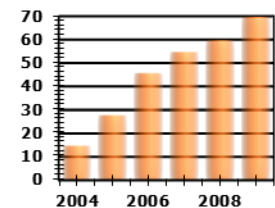
Improvement in carer-rated quality of life



Decrease in behavioral disorder



Proportion of new cases diagnosed



**Measurement of health-related quality
of life for people with dementia:
development of a new instrument
(DEMQOL) and an evaluation of
current methodology**

SC Smith, DL Lamping, S Banerjee,
R Harwood, B Foley, P Smith, JC Cook,
J Murray, M Prince, E Levin, A Mann and
M Knapp



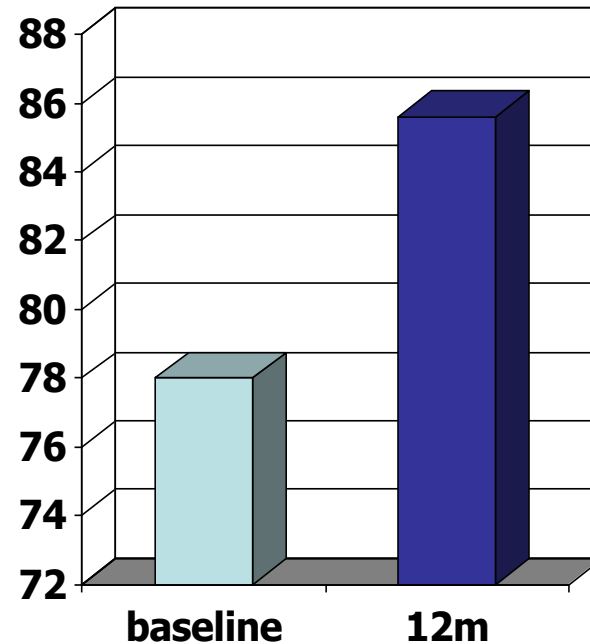
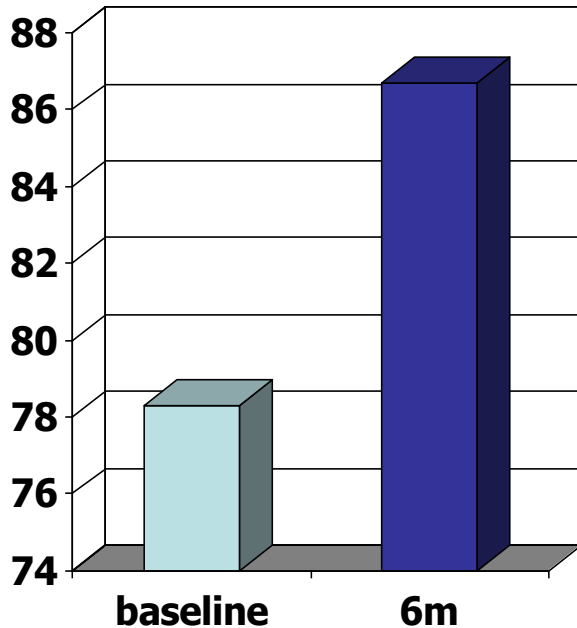
March 2005

Health Technology Assessment
NHS R&D HTA Programme



Smith et al (2005). Health Tech Ass
<http://www.nchta.org/fullmono/mon910.pdf>

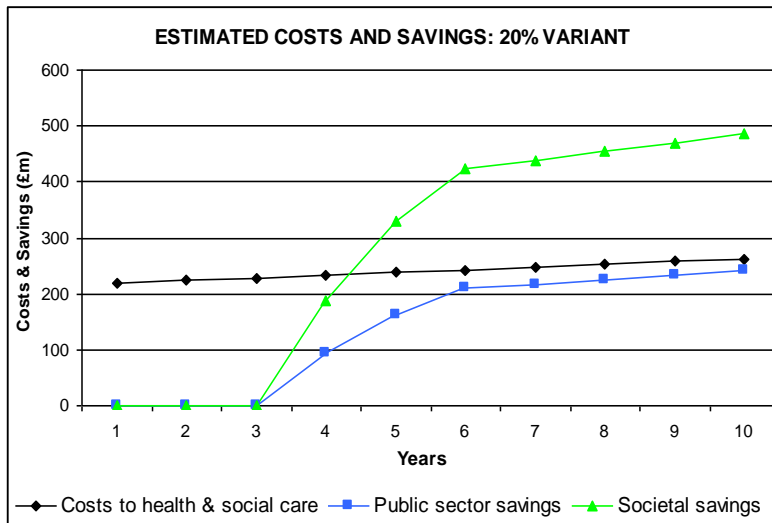
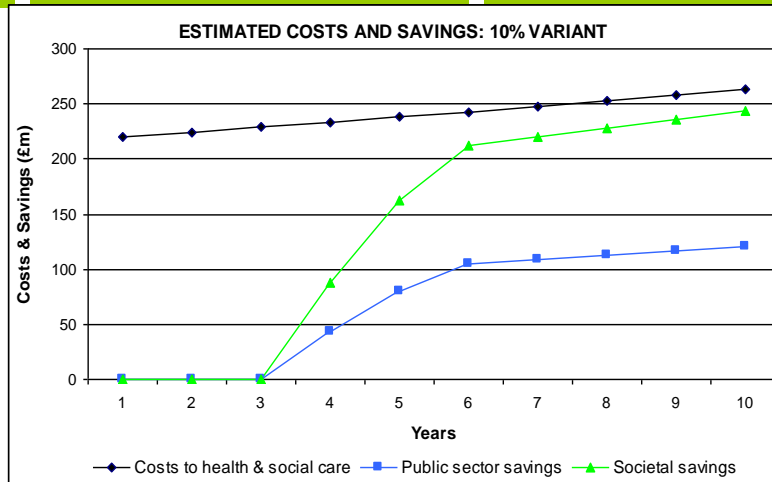
Change in DEMQOL for those below mean (<90)



- 6 month DEMQOL change 8.3pt, paired $t=4.99$, $p<0.001$, Cohen's $d = 0.79$
- 12 month DEMQOL change 7.8pt, paired $t=3.88$, $p<0.001$, Cohen's $d = 0.60$

Early intervention for dementia is clinically and cost effective – “spend to save”

- 215,000 people with dementia in care homes -- £400 per week
- Spend on dementia in care homes pa
– **£7 billion pa**
- 22% decrease in care home use with early community based care
- 28% decrease in care home use with carer support (median 558 days less)
- **Quality – older people want to stay at home, higher qol at home**
- Take an additional 220 million pa
- Delayed benefit by 5-10 years
 - Strategic head needed
- Model published by DH
- 20% releases £250 million pa y6

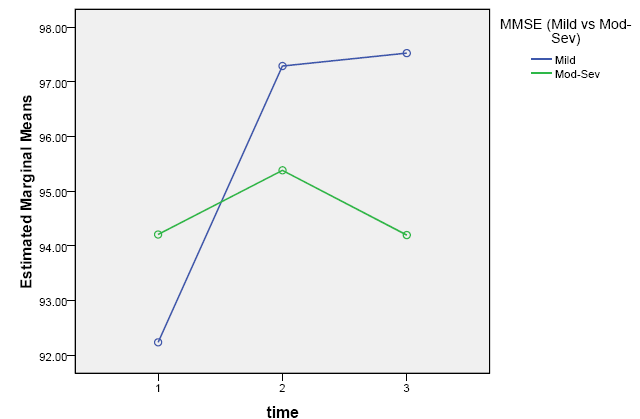
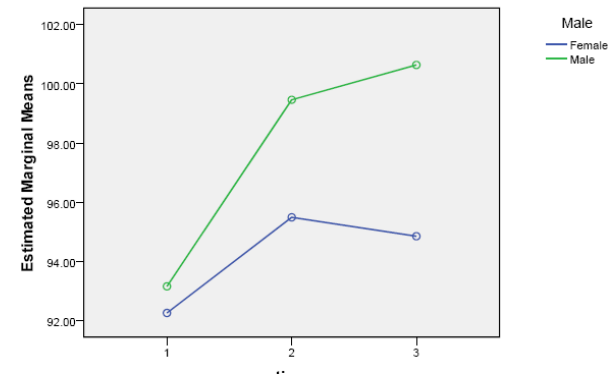
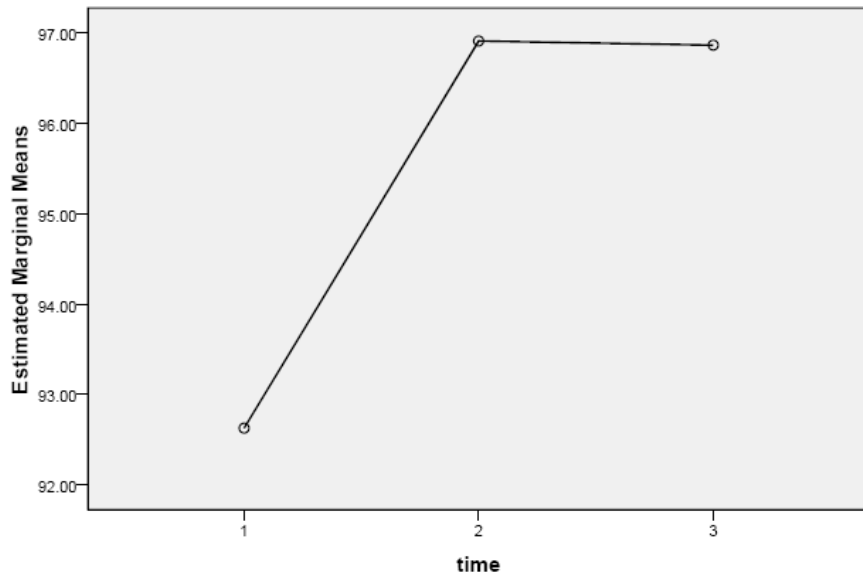


Cost effectiveness

- The Net Present Value would be positive if benefits (improved quality of life), rose linearly from nil in the first year to £250 million in the tenth year. This would be a gain of around 6,250 QALYs in the tenth year, where a QALY is valued at £40,000, or 12,500 QALYS if a QALY is valued at only £20,000.
- By the tenth year of the service all 600,000 people in England then alive with dementia will have had the chance to be seen by the new services
- A gain of 6,250 QALYS per year around 0.01 QALYs per person year. A gain of 12,500 QALYS around 0.02 QALYs per person year.
- Likely to be achievable in view of the rise of 4% reported from CMS.
- Needs only:-
 - a modest increase in average quality of life of people with dementia,
 - plus a 10% diversion of people with dementia from residential care, to be cost-effective.
- The net increase in public expenditure would then, be justified by the expected benefits.

Changes over time in real world clinical practice, DEMQOL scores from the Croydon Memory Service

- routine practice
- data from patients remaining in service
- baseline, 6 months and 12 months
- indication of the possibility of change
- one element of responsiveness



Tracking cases on GP QOF dementia registers



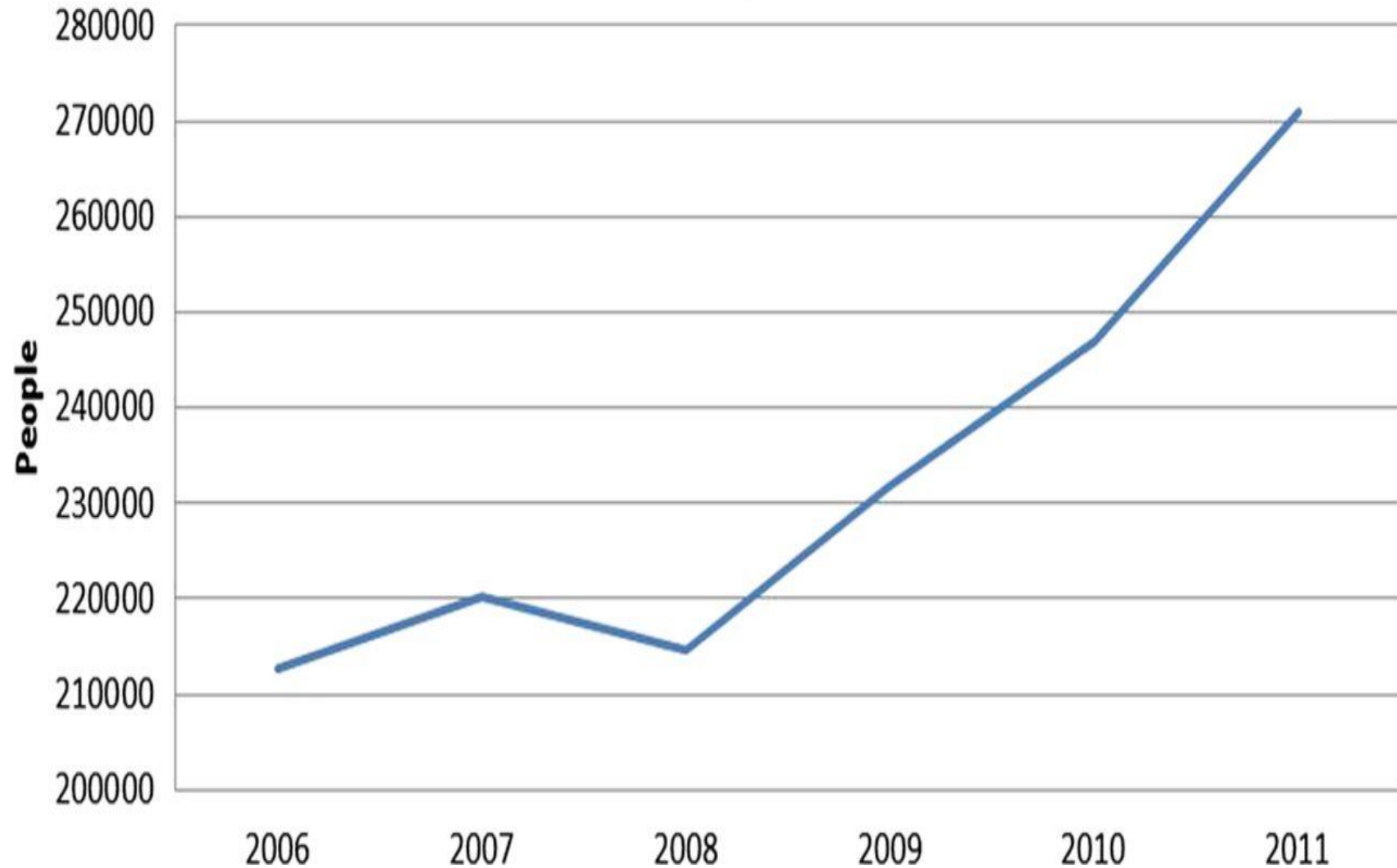
Mapping the Dementia Gap 2012

Progress on improving diagnosis of dementia 2011-2012

- ❑ 2011 – 294,000 (41.4%)
- ❑ 2012 – 323,000 (44.3%)

**Number without a
diagnosis 2012
407,000**

Number of people on QOF registers with dementia in England 2006/07 - 2011/12*



Production of health and wellbeing in dementia – role of memory services

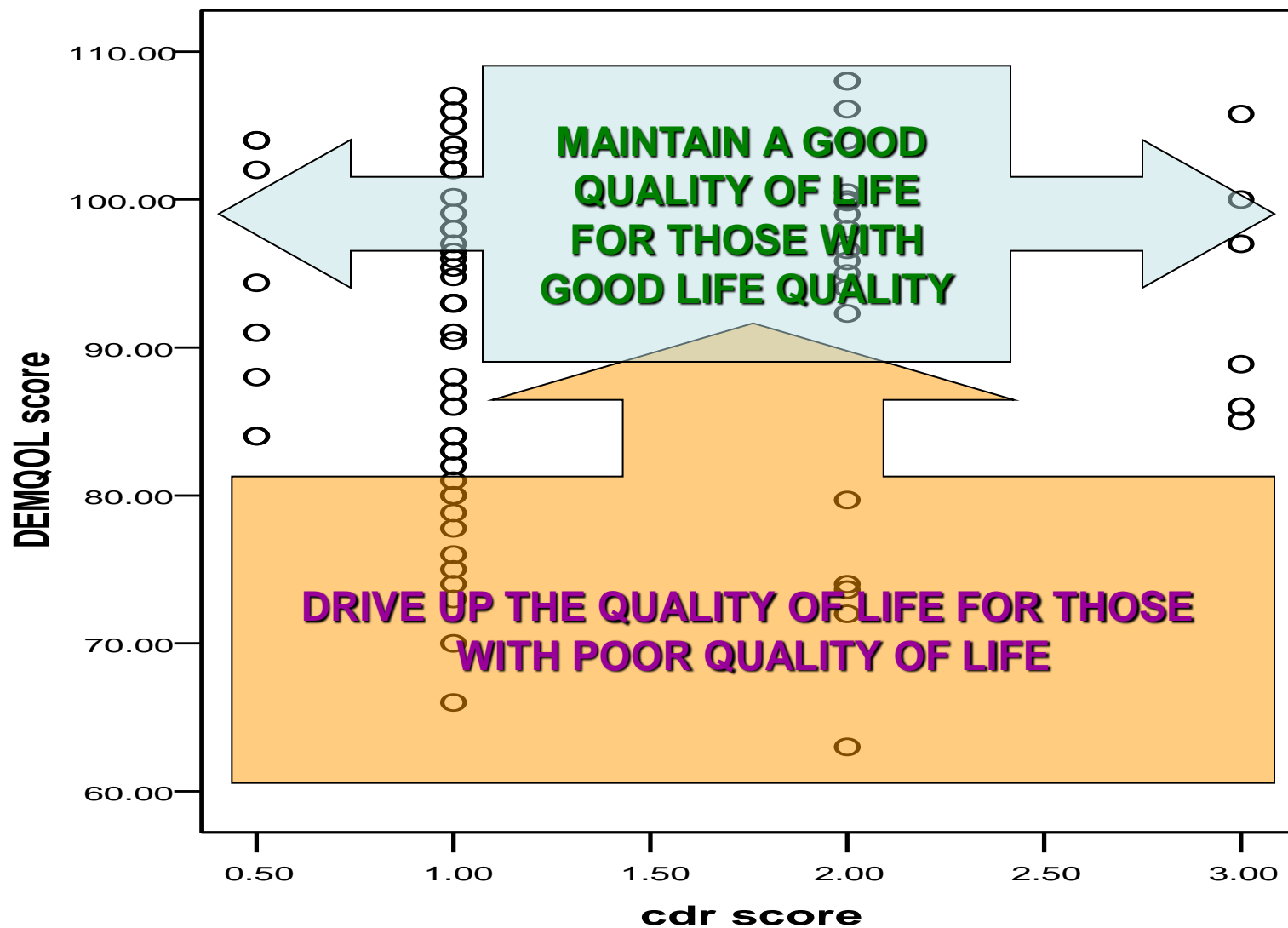


**How we turn people with worrying symptoms
into people who know what is going on**

**How we turn toxic uncertainty
into empowered understanding**

**How we enable choice, self-efficacy
and quality of life and quality of care**

Distribution of DEMQOL scores by CDR score





Reasons to be cheerful part 3

BETTER PREVENTION AND TREATMENT OF DEMENTIA

The Lancet, Volume 382, Issue 9902, Pages 1405 - 1412, 26 October 2013
doi:10.1016/S0140-6736(13)61570-6 [Cite or Link Using DOI](#)

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A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II

Fiona E Matthews PhD [a](#), Prof Antony Arthur PhD [b](#), Linda E Barnes RGN [c](#), Prof John Bond BA [d](#), Prof Carol Jagger PhD [d](#), Prof Louise Robinson MD [d](#), Dr Prof Carol Brayne MD [e](#) [✉](#), on behalf of the Medical Research Council Cognitive Function and Ageing Collaboration

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Published Online: 17 July 2013

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Good news on dementia prevalence—we can make a difference

[Sube Banerjee](#) [✉](#)

The findings of the Cognitive Functioning and Ageing Study (CFAS) I and II are unequivocally good news. New data, reported in *The Lancet*,¹ suggest that the prevalence of dementia in the UK in 2011 was significantly lower than would have been expected based on the estimated prevalence in 1991. For CFAS I, data were taken from three geographical areas—Cambridgeshire, Newcastle, and Nottingham—to generate an estimate of the prevalence of dementia in the UK in 1991. This was based on a

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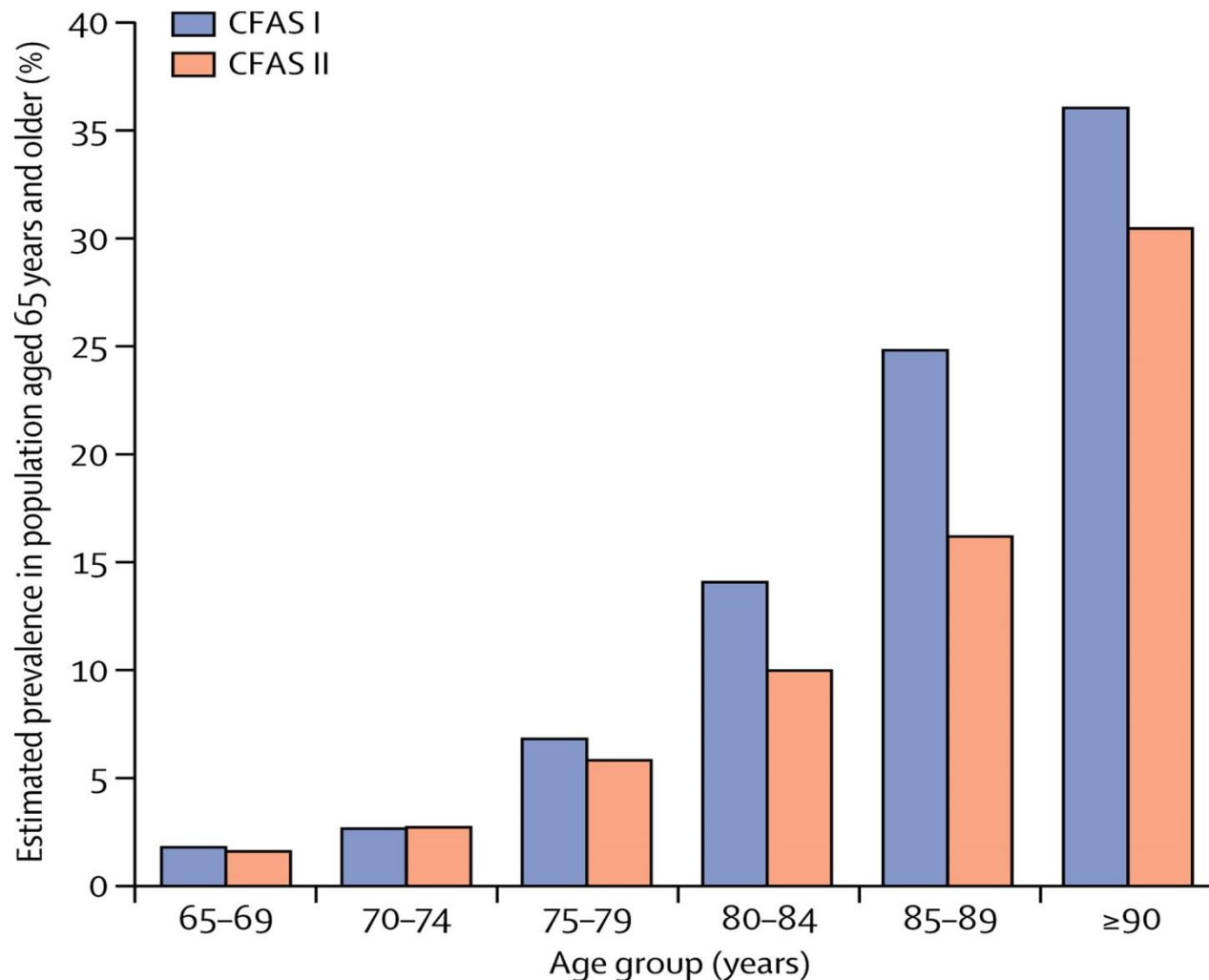
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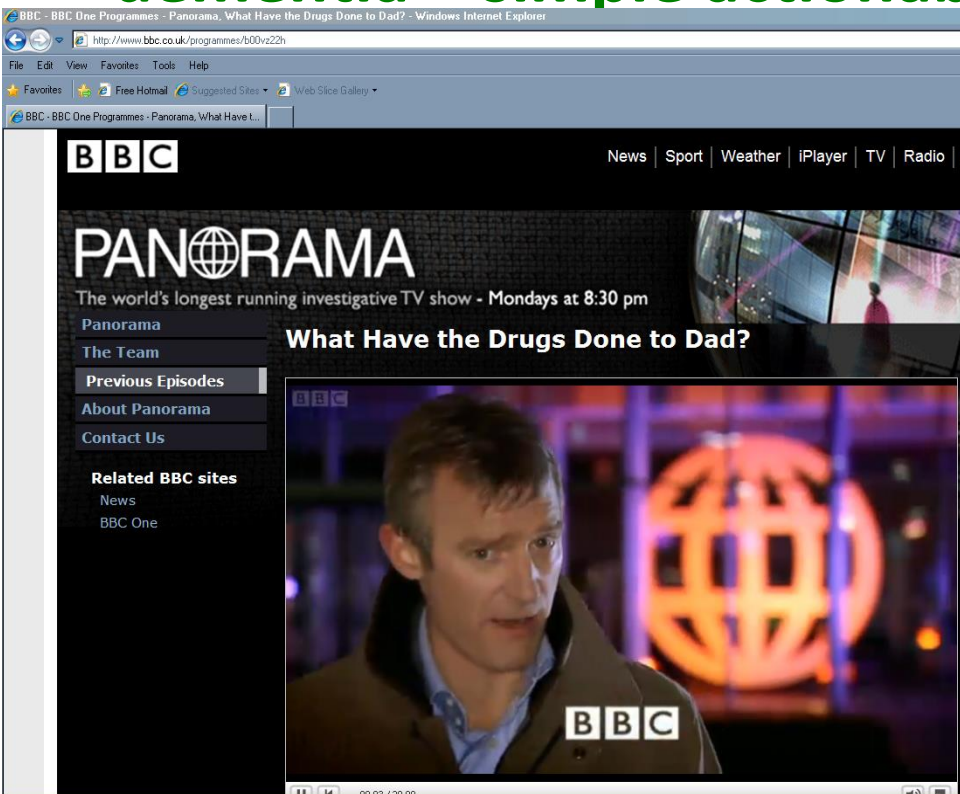
Articles A two-decade comparison of prevalence of

CFAS I and CFAS II age-specific dementia prevalence



[The Lancet 2013; 382:1405-1412](#)

Ministerial review of use of antipsychotics in dementia – simple actionable messages from research



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What Have the Drugs Done to Dad?

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BBC News - Doctors told to cut anti-psychotic drugs for dementia - Windows Internet Explorer

http://www.bbc.co.uk/news/uk-11645889

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1 November 2010 Last updated at 10:20

Doctors told to cut anti-psychotic drugs for dementia

The use of anti-psychotic drugs for dementia patients must be cut by two-thirds by November 2011, the minister responsible has warned doctors.

Care Services Minister Paul Burstow told Panorama that GPs must "take responsibility" and drastically reduce the amount of drugs being prescribed.

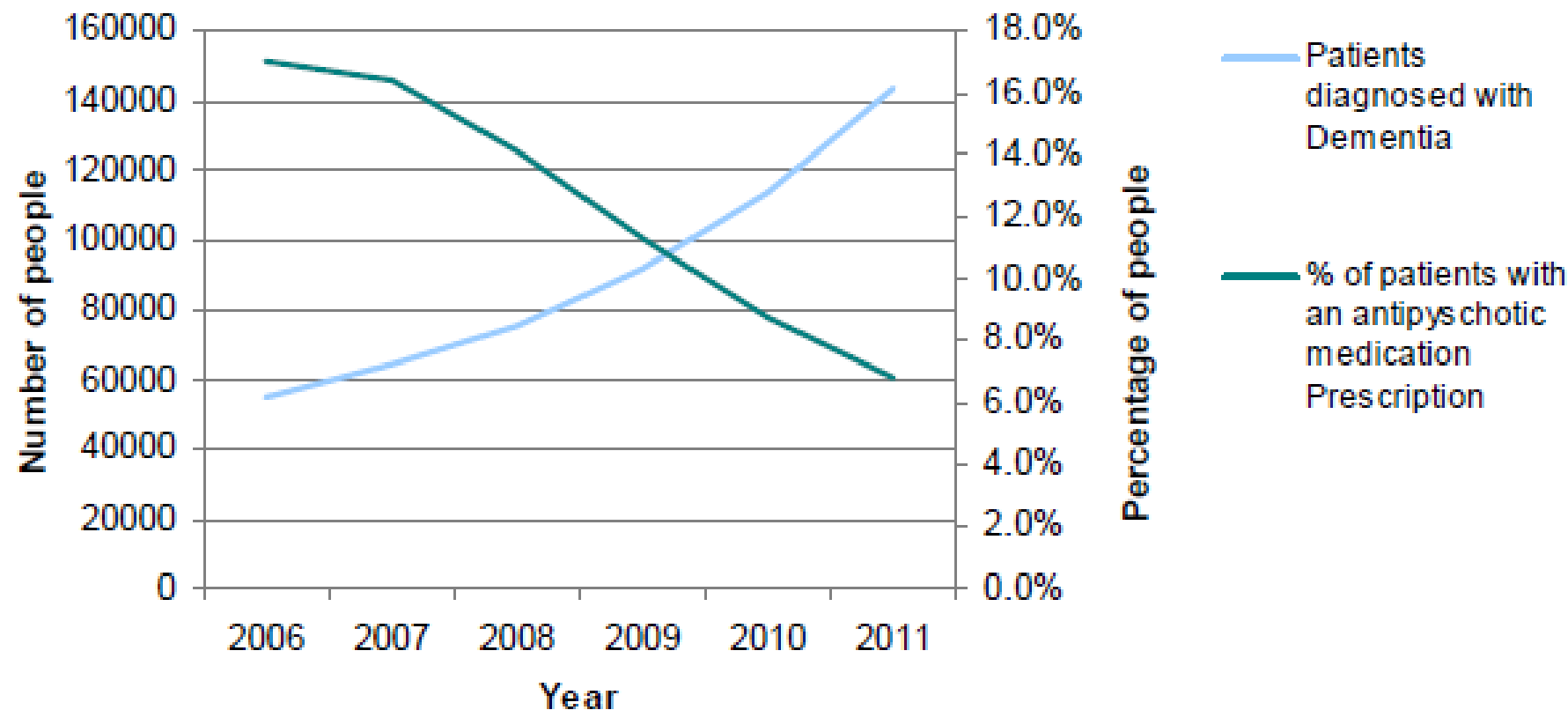
Evidence suggests the drugs - used to control aggressive behaviour - have dangerous side effects.

A leading GP said most doctors agree that their use needs to be curtailed.

PAUL BURSTOW MP
Minister for Health Care Services

An independent report commissioned and funded by the Department of Health

National Audit of antipsychotics in dementia 2012



The acute end of the dementia pathway



- 70% hospital beds occupied by older people, half of them have dementia
- Dementia is a predictor of increased LOS, poorer outcomes and institutionalisation
- 30% of elderly patients with dementia, admitted into acute hospitals from their own homes are discharged into care homes

Evaluation RAID model – old age psychiatric liaison services in a general hospital

**Saving 12m - 12,951 bed days
35 beds per day - £3m pa**

**8% increase admission
prevention
6 beds per day**

**Discharge home
Before 34% - after 67%**

**Readmission rates
Before 19% - after 5%**

Reducing Length
of Stay

Increasing rates
of discharge at
MAU

A&E diversion

More home
discharges

Reducing rates
of re-admissions

**Total savings:
£3.55 million to NHS**

**Money value
Cost: return = £1:£4**

At least 44 beds/day

**£60,000/week to social
care cost**

The need for action

“No other force is likely to shape the future of national economic health, public finances and national policies as the irreversible rate at which the world’s population is growing older...”

S&P numbers take the debt from about 4.7% of GDP now to about 7.5% in the next decade

Global Aging 2010: An Irreversible Truth

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Secondary Contacts:

David T. Boers, London (44) 20-7176-7101; david_boers@standardandpoors.com

Ivan Montzov, London (44) 20-7176-7159; ivan_montzov@standardandpoors.com

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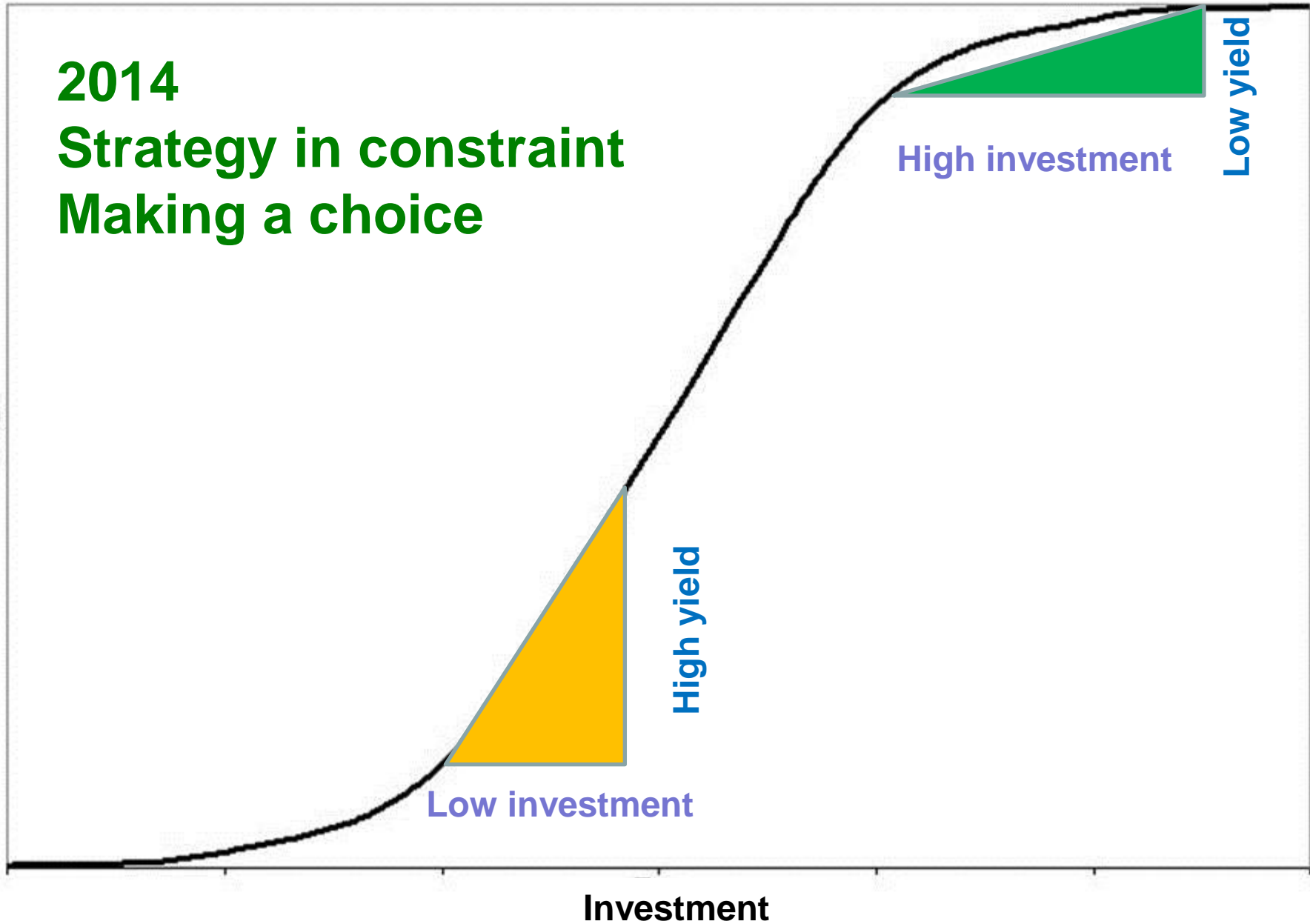
The Policy Implications Of Closing The Gap

From Bad To Worse: Comparison With Previous Standard & Poor's Reports On Population Aging

A Global Challenge

2014
Strategy in constraint
Making a choice

Yield





Thank you!