

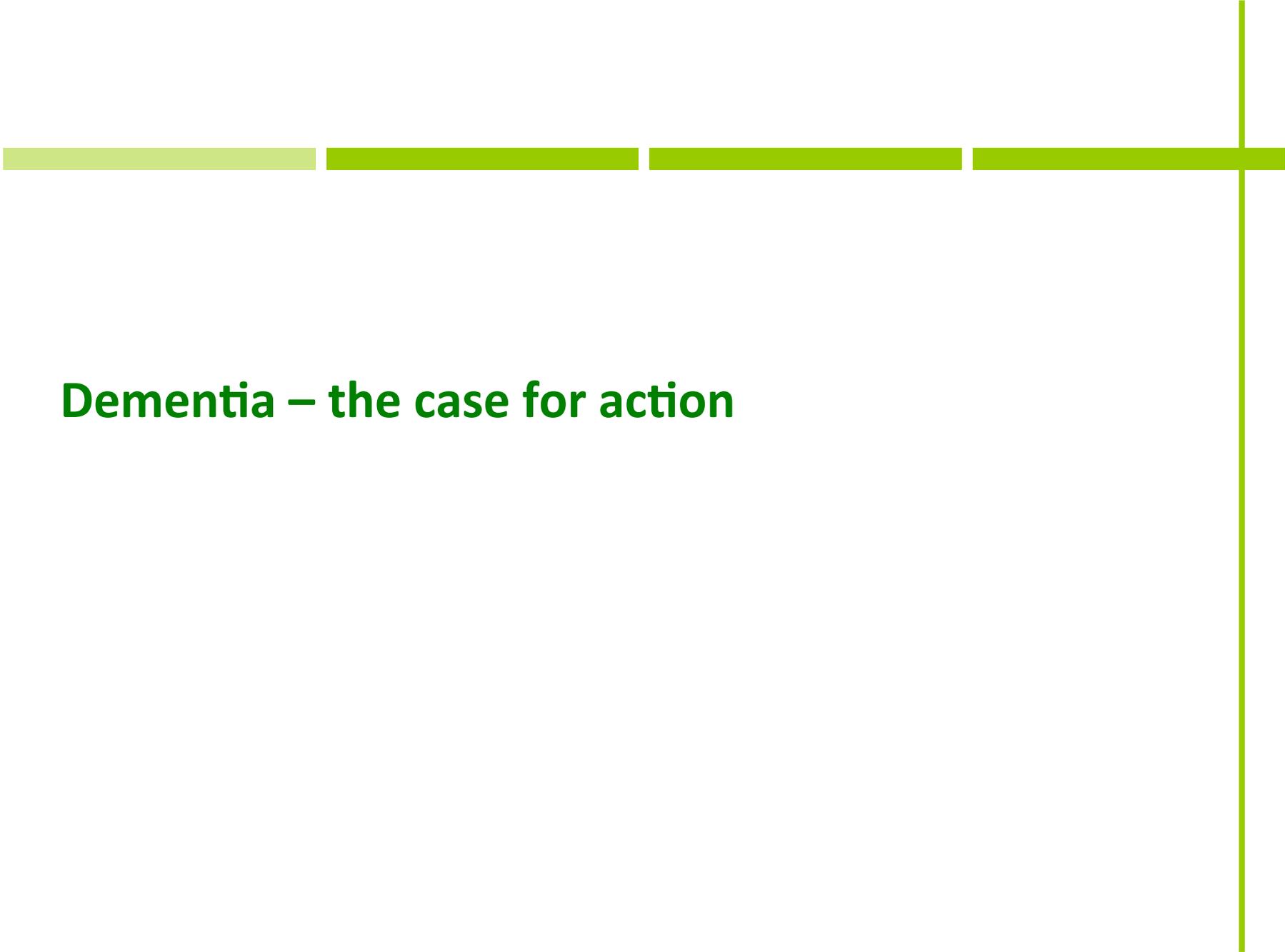


The role of memory services in delivering good quality care for people with dementia

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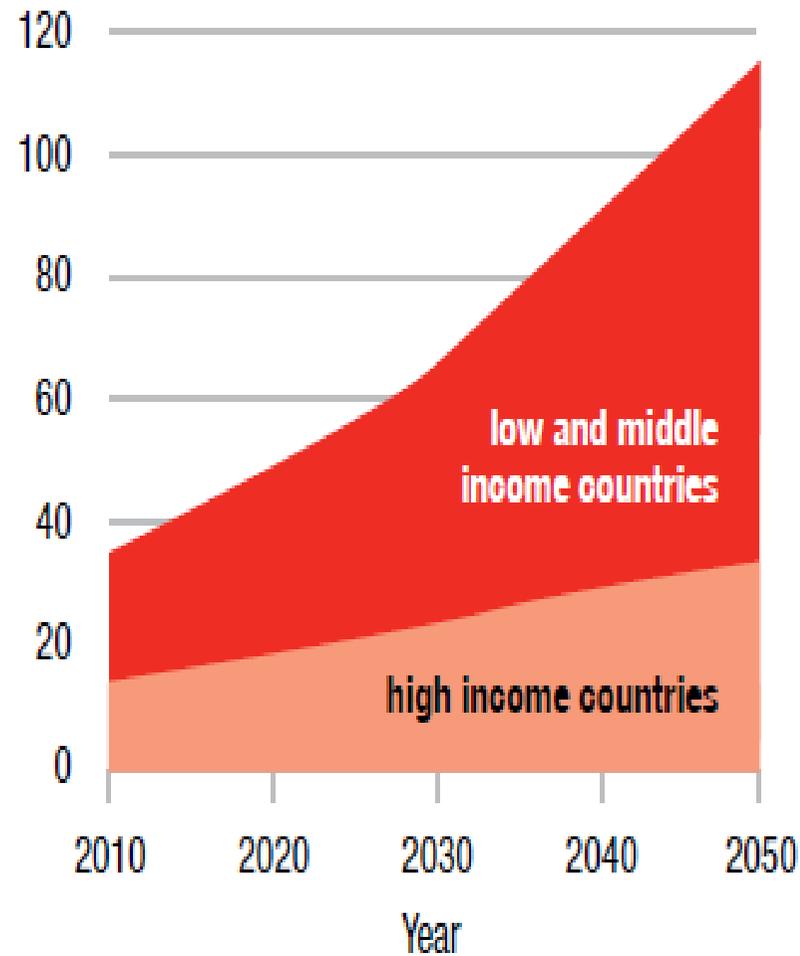




Dementia – the case for action

Growth of numbers of people with dementia

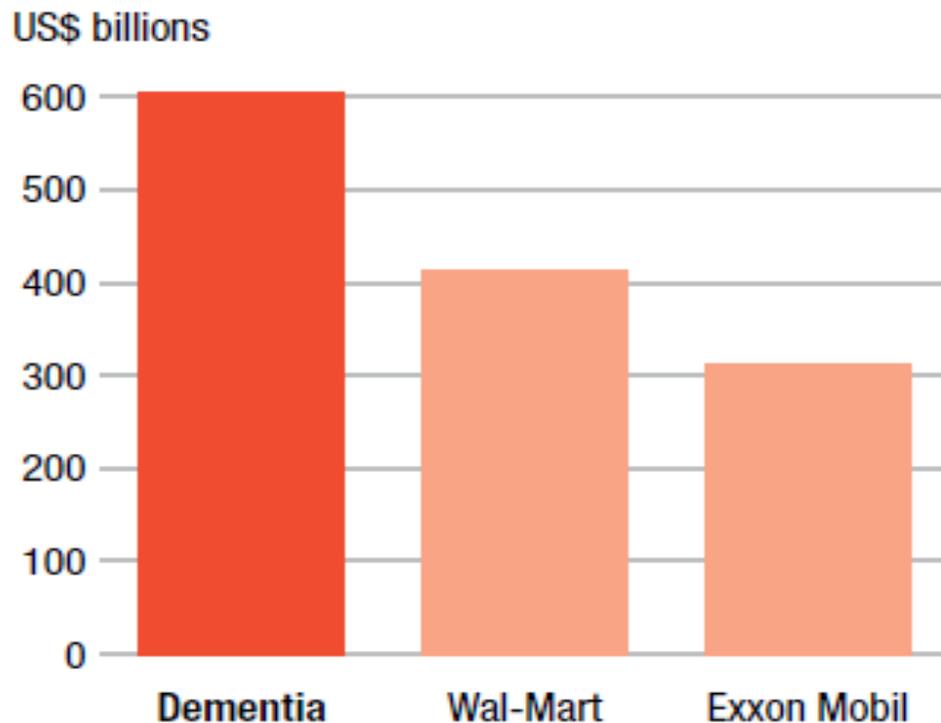
Numbers of people with dementia (millions)



- **The World Alzheimer Report (2009) estimated:**

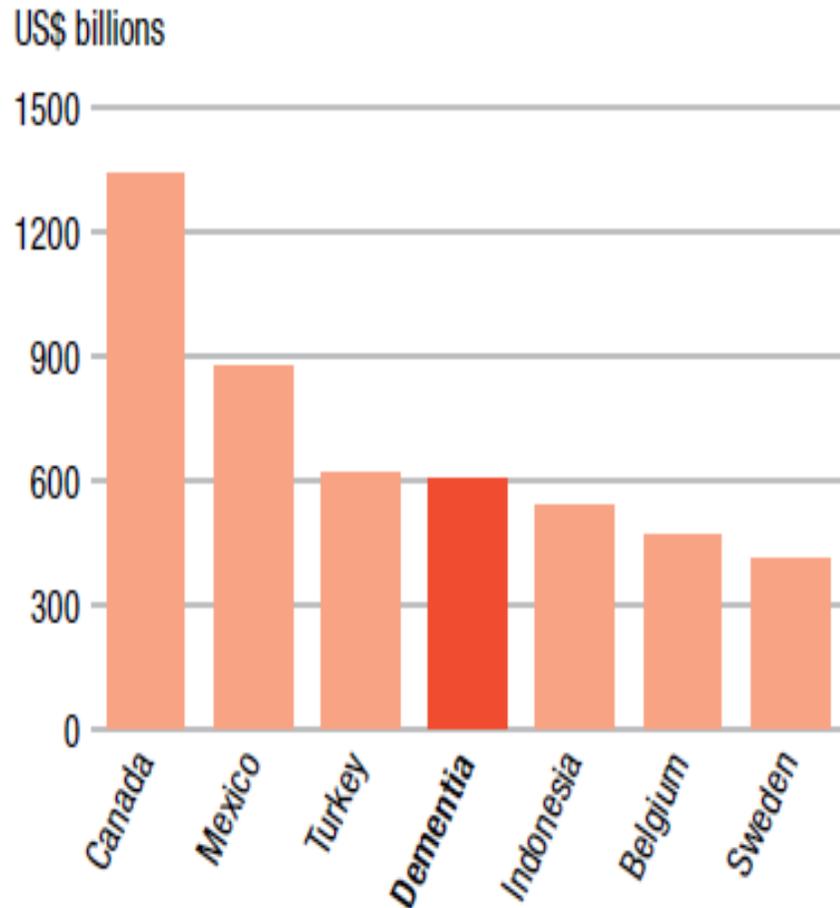
- **35.6 million people living with dementia worldwide in 2010**
- **Increasing to 65.7 million by 2030**
- **115.4 million by 2050**

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



...so how are we doing?

"I've got it too Omar... a strange feeling like we've just been going in circles"



National dementia strategies

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



England - background

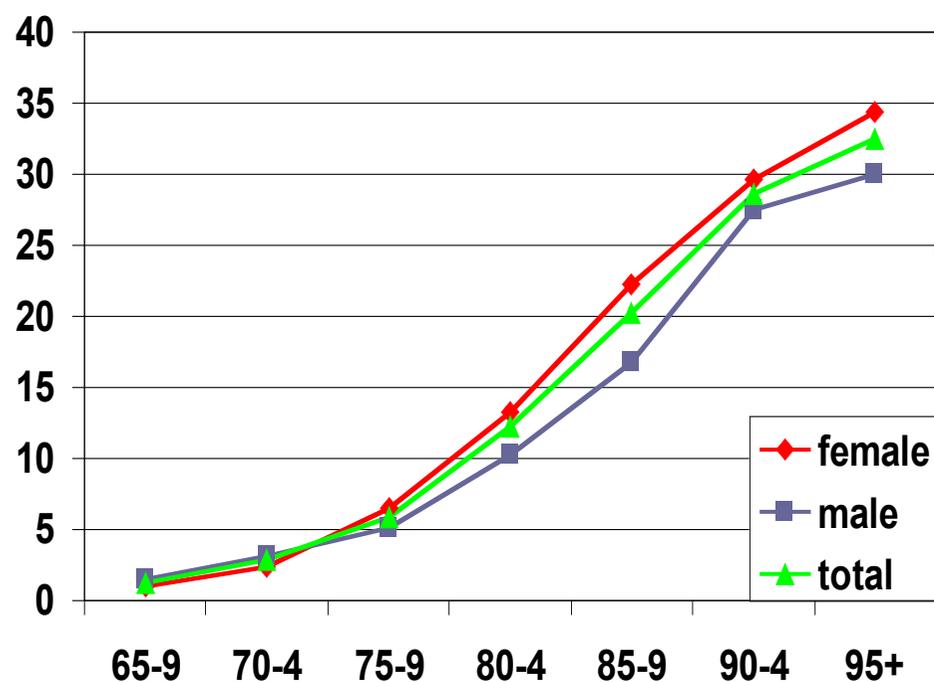


- Population 50 million
- 16% over 65
- Life Expectancy at Birth
 - Males: 76.9 years
 - Females: 81.1 years
- Religion
 - Christian: 72%
 - Jedi: 0.7% (350,000)
 - Sith: 0.001% (500)

Bringing it home, the local case - Dementia UK Report

simple messages – common and costly

Population prevalence (%) of dementia
by age

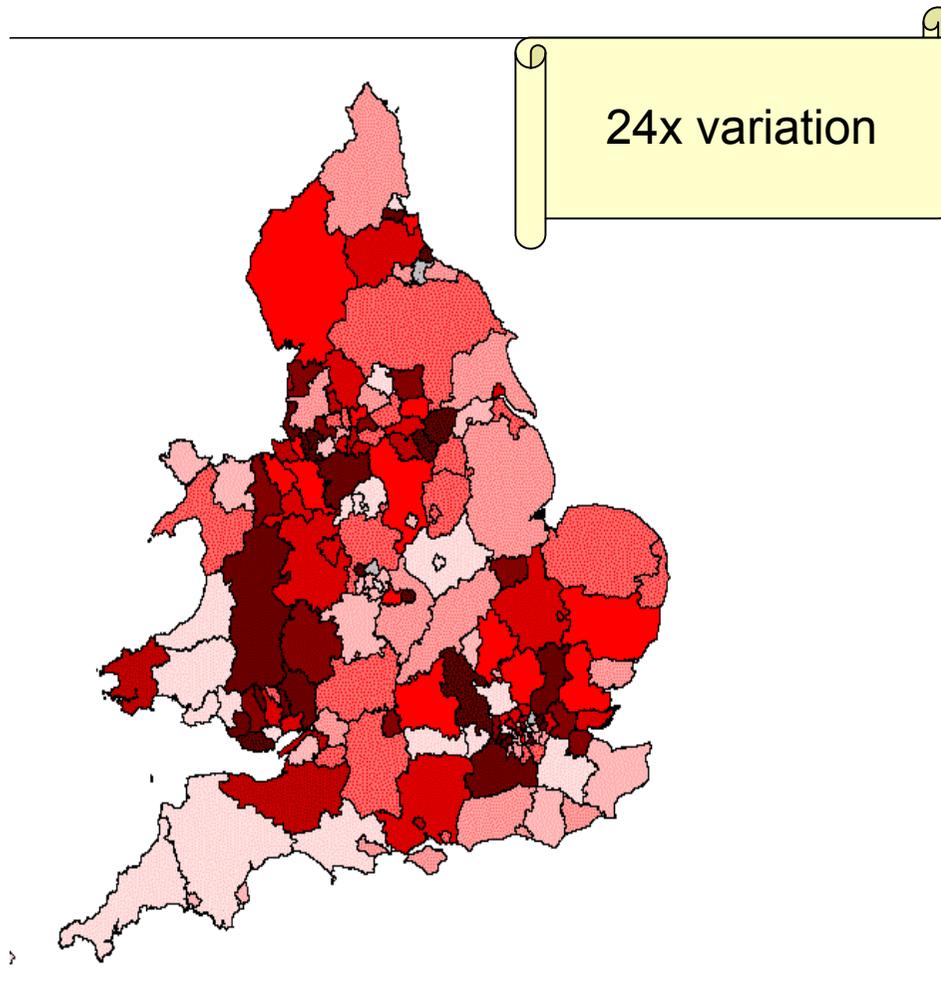


- Numbers with dementia **700,000**
In 30 years – doubling to **1.4 m**
- UK dementia cost - **£17billion pa**
In 30 years – tripling **£51billion pa**

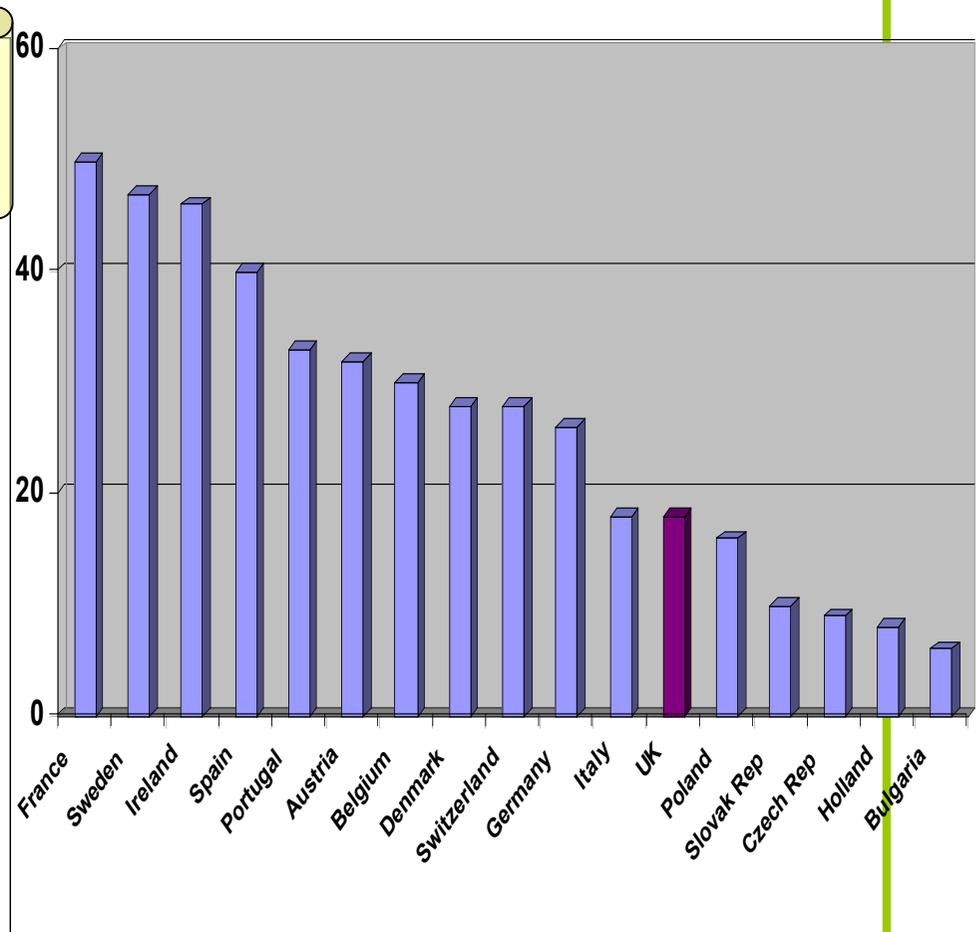
Knapp et al (2007)

Dementia UK Report simple messages – under-recognised, under-treated

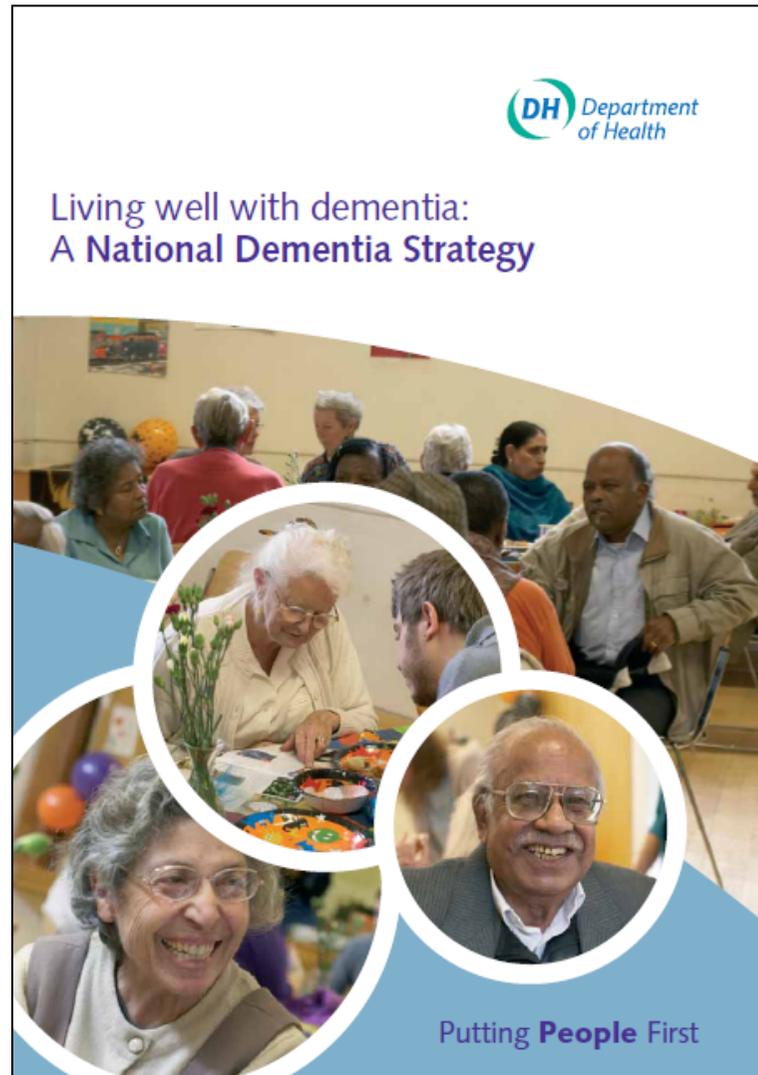
Variation in treatment and diagnosis of dementia in the UK



Variation in treatment and diagnosis of dementia across Europe

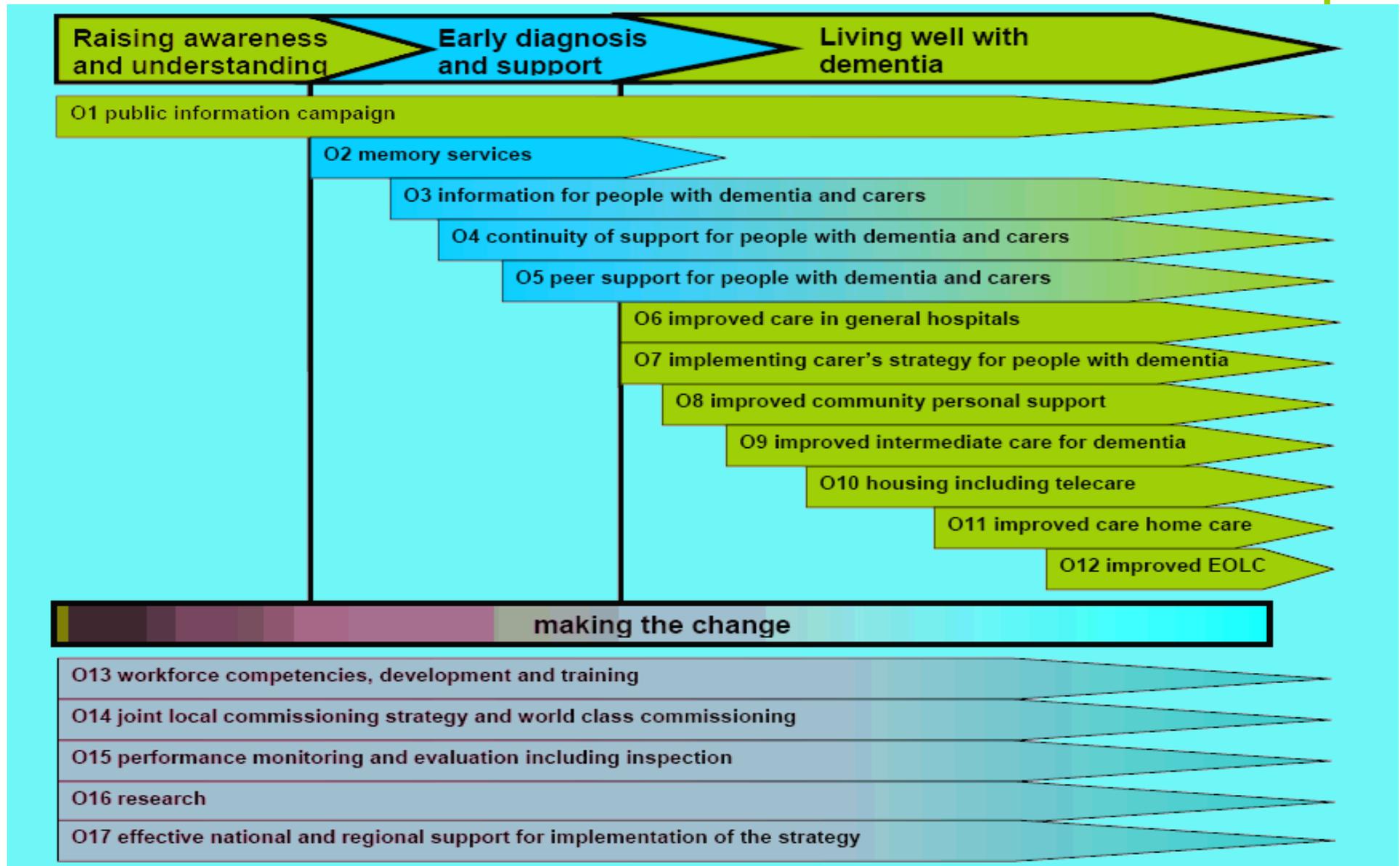


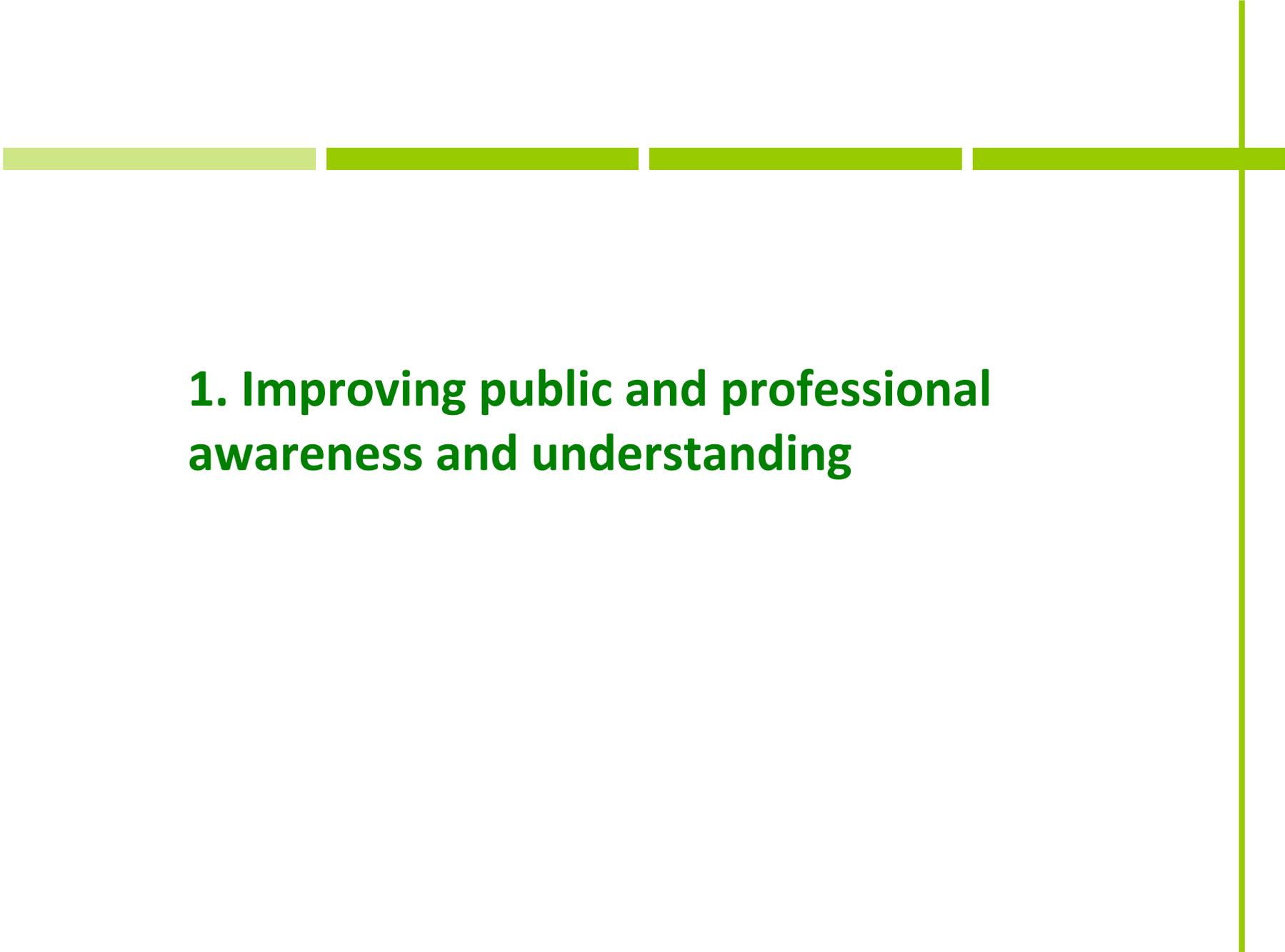
National Dementia Strategy - England



- Published 2 Feb 2009
- Five year plan
- 17 interlinked objectives
- £150 million extra funding
- Four key themes
 - Improving awareness
 - Early and better diagnosis
 - Improved quality of care
 - Delivering the Strategy

Objectives of the National Dementia Strategy





1. Improving public and professional awareness and understanding

Sometimes what we know is wrong

He's one of the busiest men in town. While his door may say *Office Hours 2 to 4*, he's actually on call 24 hours a day.

The doctor is a scientist, a diplomat, and a friendly sympathetic human being all in one, no matter how long and hard his schedule.

According to a recent Nationwide survey:

MORE DOCTORS SMOKE CAMELS THAN ANY OTHER CIGARETTE

DOCTORS in every branch of medicine—113,597 in all—were queried in this nationwide study of cigarette preference. Three leading research organizations made the survey. The gist of the query was—What cigarette do you smoke, Doctor?

The brand named most was Camel!

The rich, full flavor and cool mildness of Camel's superb blend of costlier tobaccos seem to have the same appeal to the smoking tastes of doctors as to millions of other smokers. If you are a Camel smoker, this preference among doctors will hardly surprise you. If you're not—well, try Camels now.

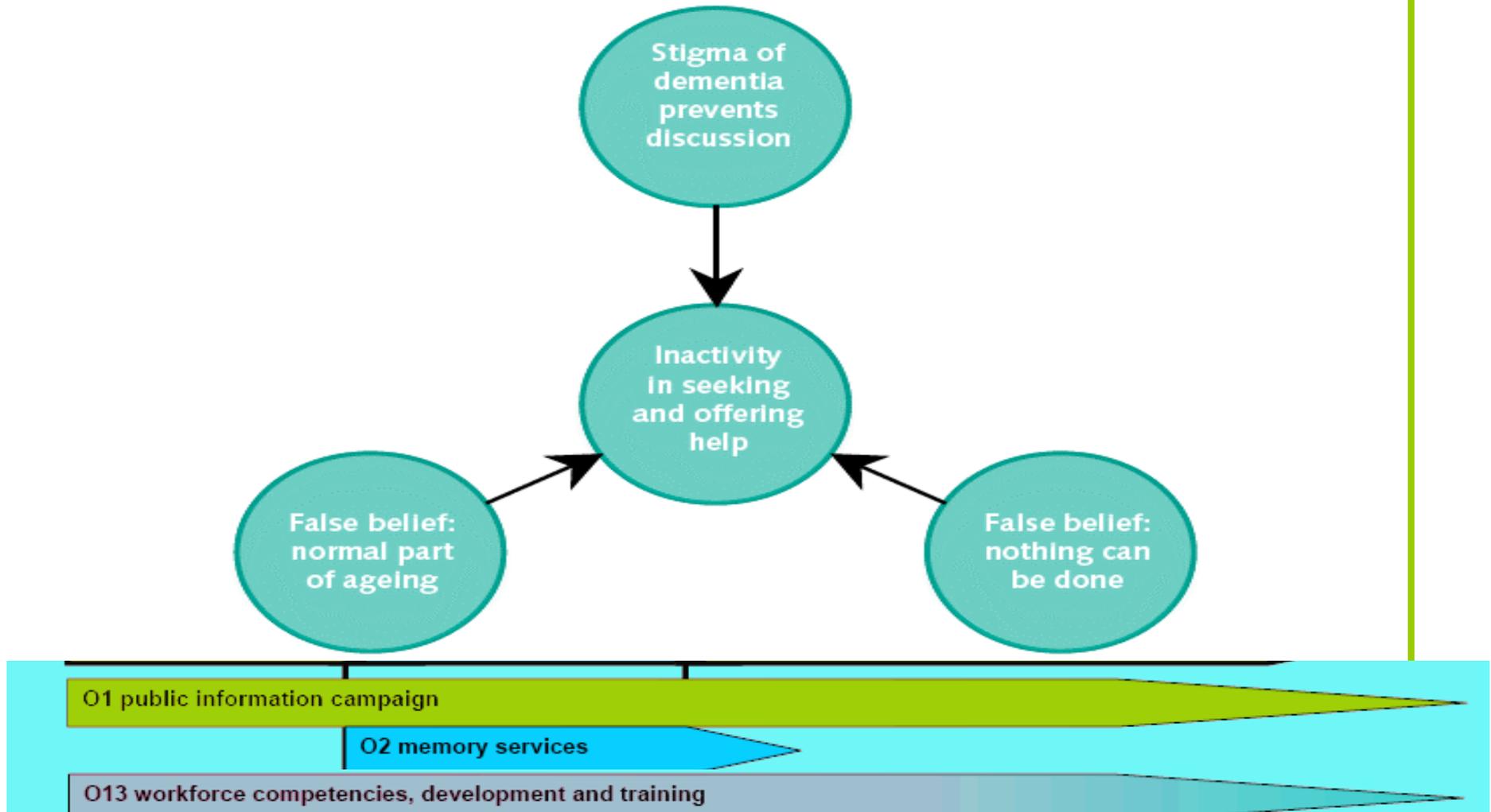
Your "T-Zone" Will Tell You...

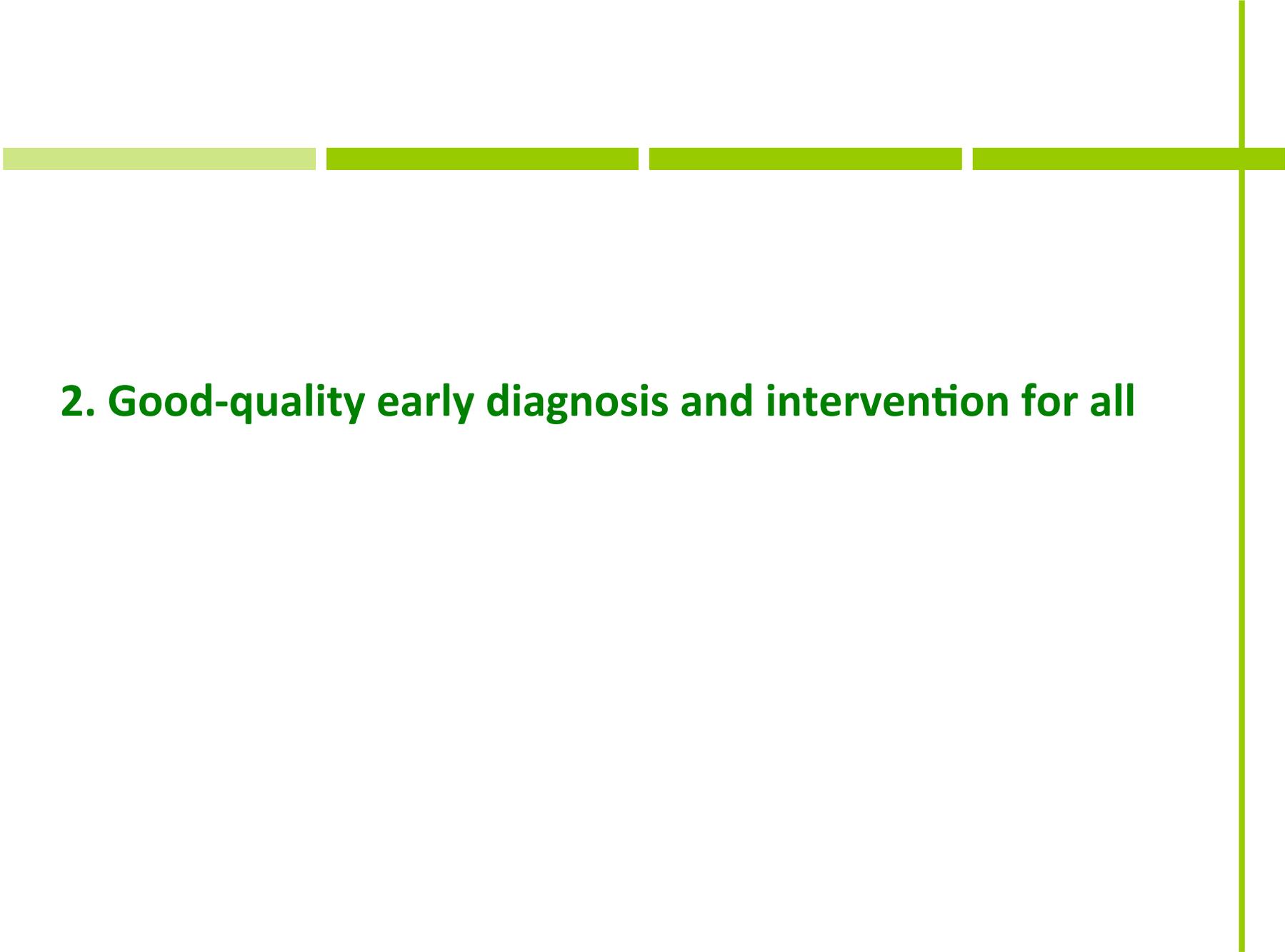
T for Taste . . .
T for Throat . . .

that's your proving ground for any cigarette. See if Camels don't suit your "T-Zone" to a "T."

CAMELS Costlier Tobaccos

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

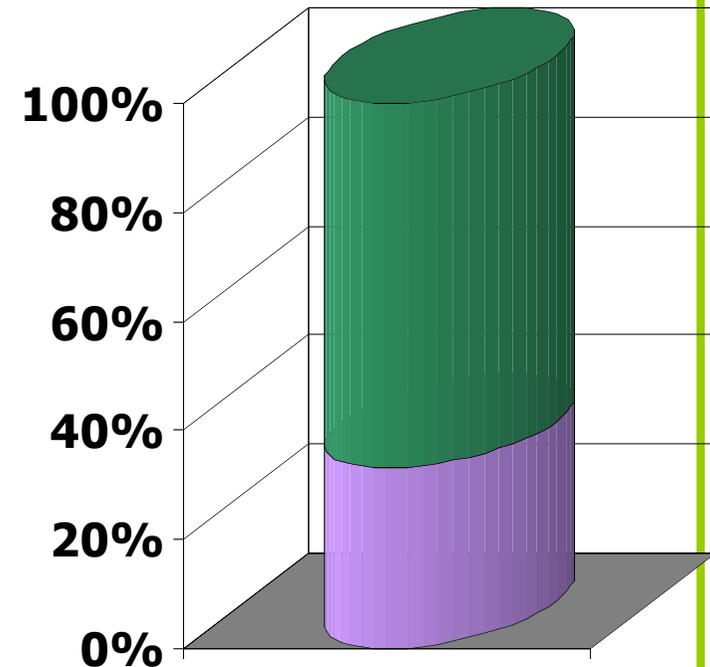




2. Good-quality early diagnosis and intervention for all

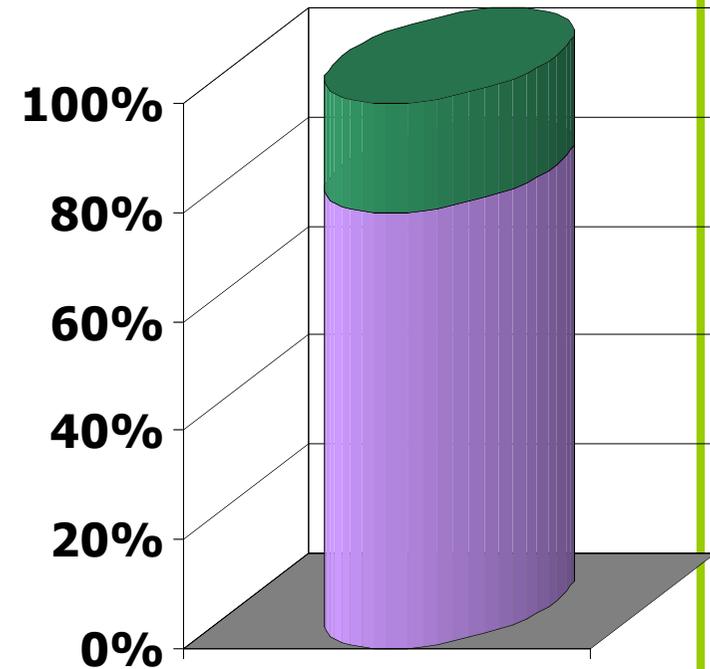
The fundamental problem - now

- Only a third at most 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

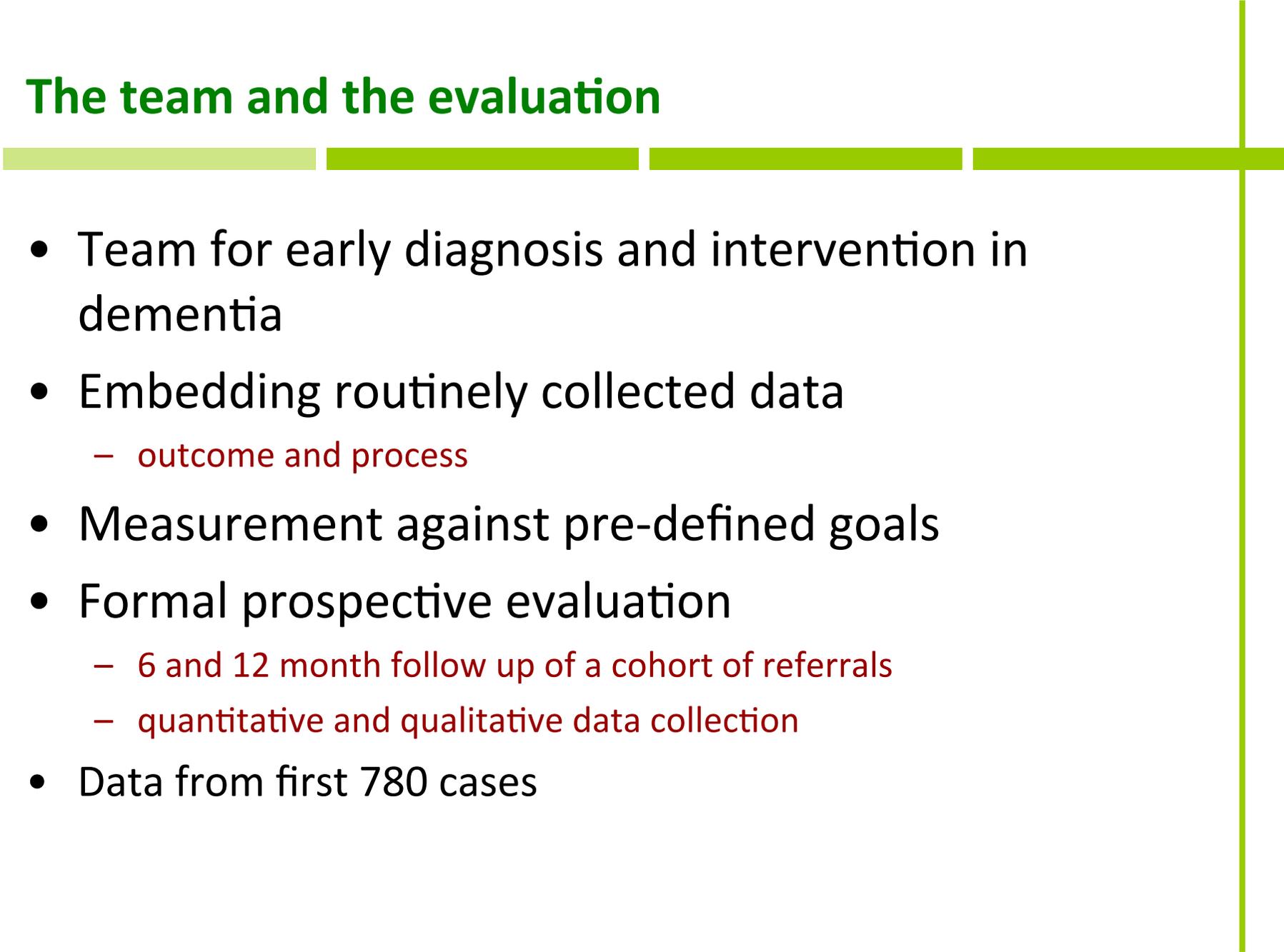


The solution

- 80% of people with dementia receive specialist health care assessment or 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



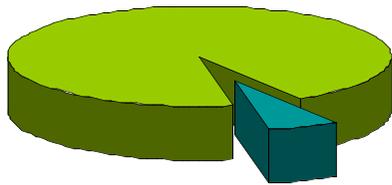
The team and the evaluation



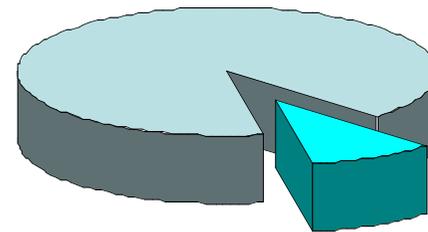
- Team for early diagnosis and intervention in dementia
- Embedding routinely collected data
 - outcome and process
- Measurement against pre-defined goals
- Formal prospective evaluation
 - 6 and 12 month follow up of a cohort of referrals
 - quantitative and qualitative data collection
- Data from first 780 cases

What is good quality care? - data on first 780 cases

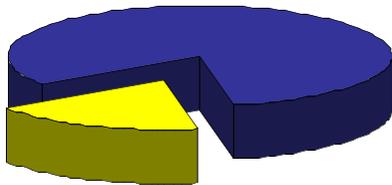
95% acceptance rate



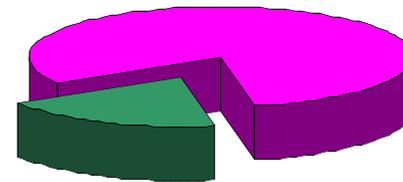
94% appropriate referrals



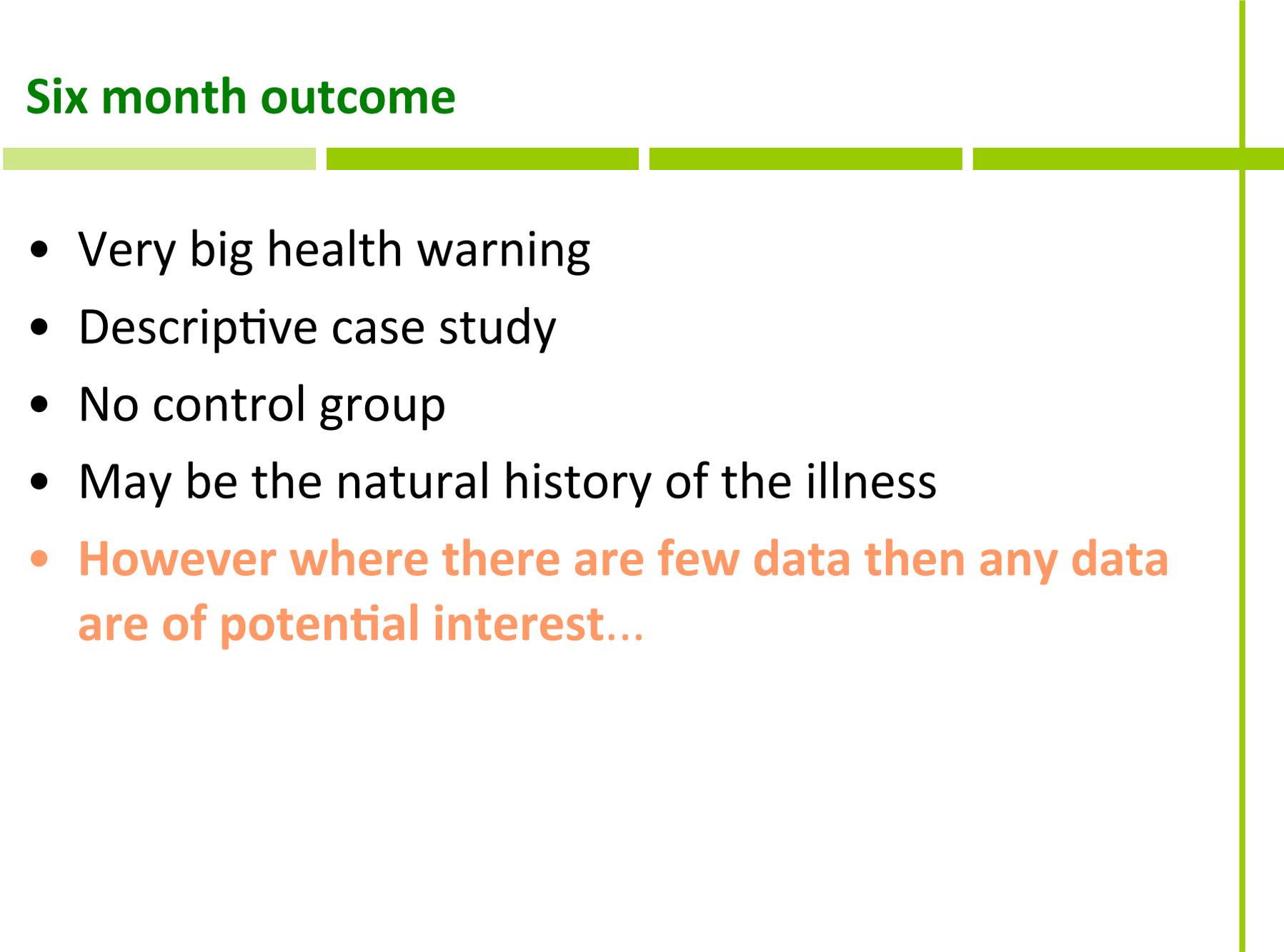
18% minority ethnic groups



19% under 65 years of age



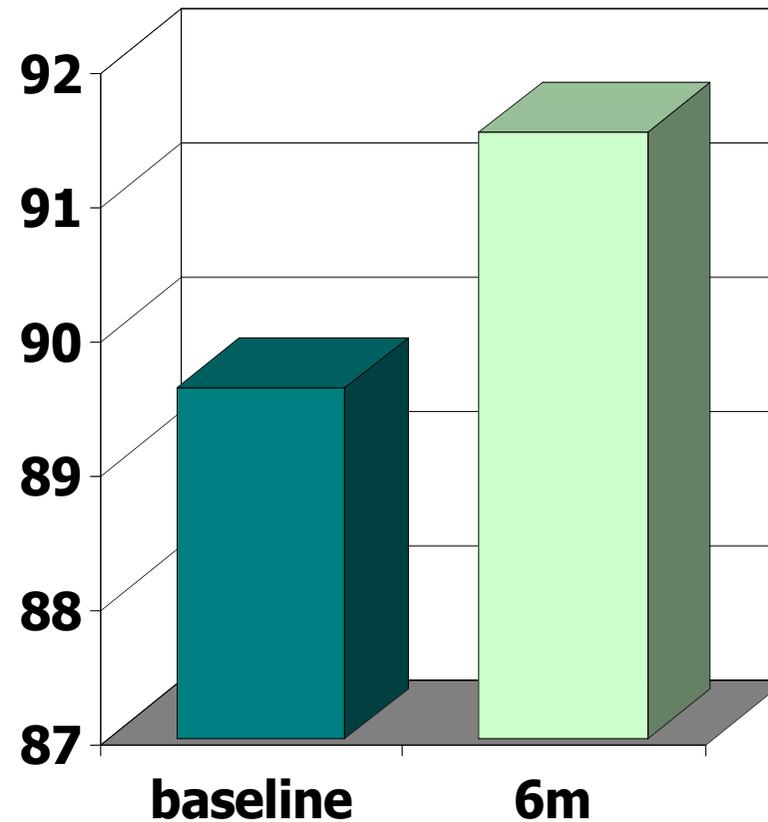
Six month outcome



- Very big health warning
- Descriptive case study
- No control group
- May be the natural history of the illness
- **However where there are few data then any data are of potential interest...**

Outcome: improvement in self-rated quality of life - DEMQOL

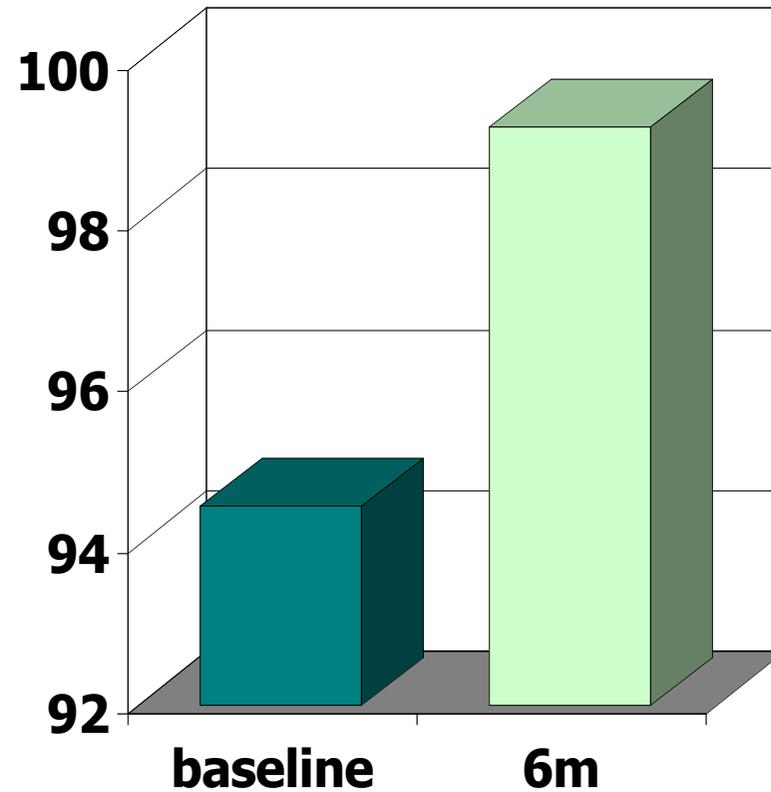
- Part of routine assessment
- Preliminary data
- 109 cases
- 6 month follow-up
- $p=0.029$



Banerjee et al (2007) IJGP

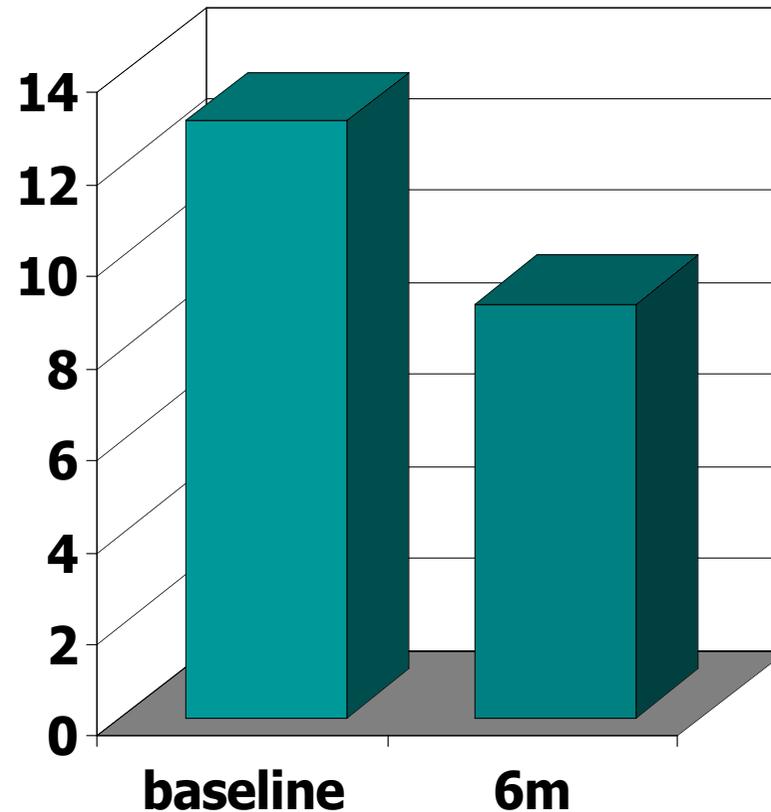
Outcome: improvement in proxy-rated quality of life – DEMQOL-Proxy

- Part of routine assessment
- Preliminary data
- 141 cases
- 6 month follow-up
- $p=0.041$



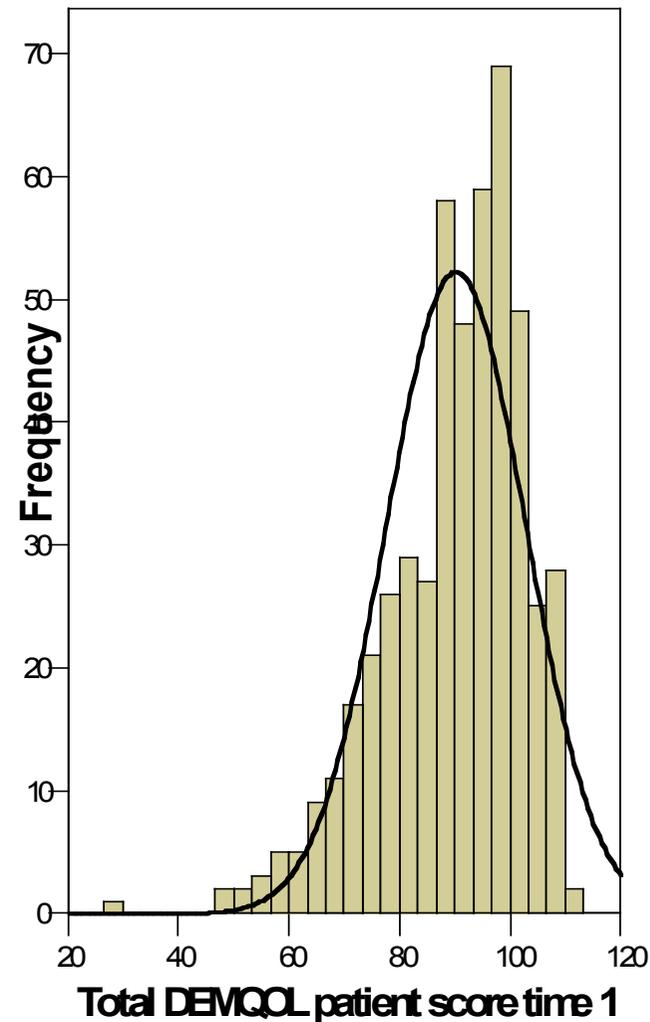
Outcome: decrease in behavioural disturbance - NPI

- Preliminary data
- 90 cases
- 6 month follow-up
- $p=0.001$



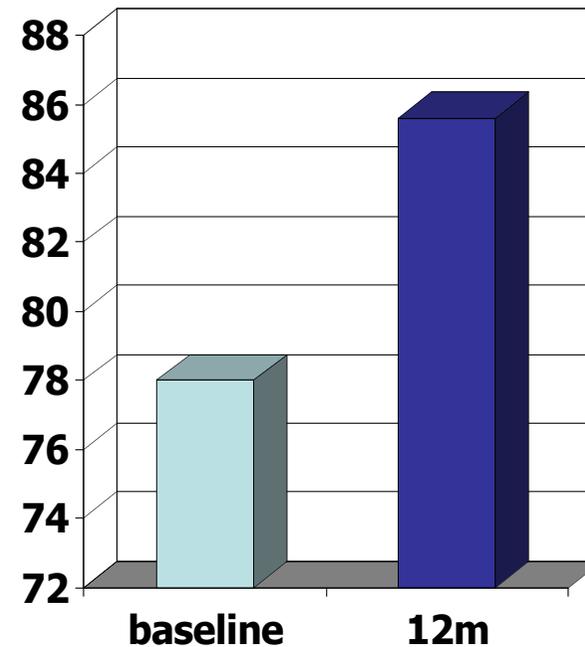
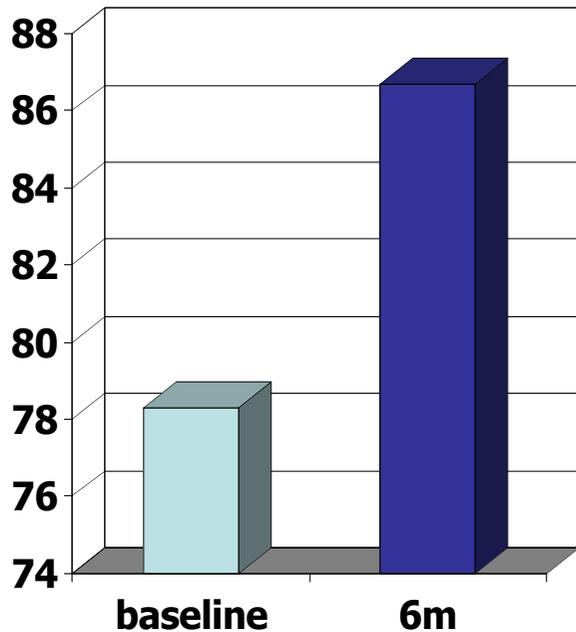
What sort of variable is quality of life?

- Do we just treat it as a continuous variable?
- Do we want to define those with impaired qol?
- Model with those under the mean score (90)



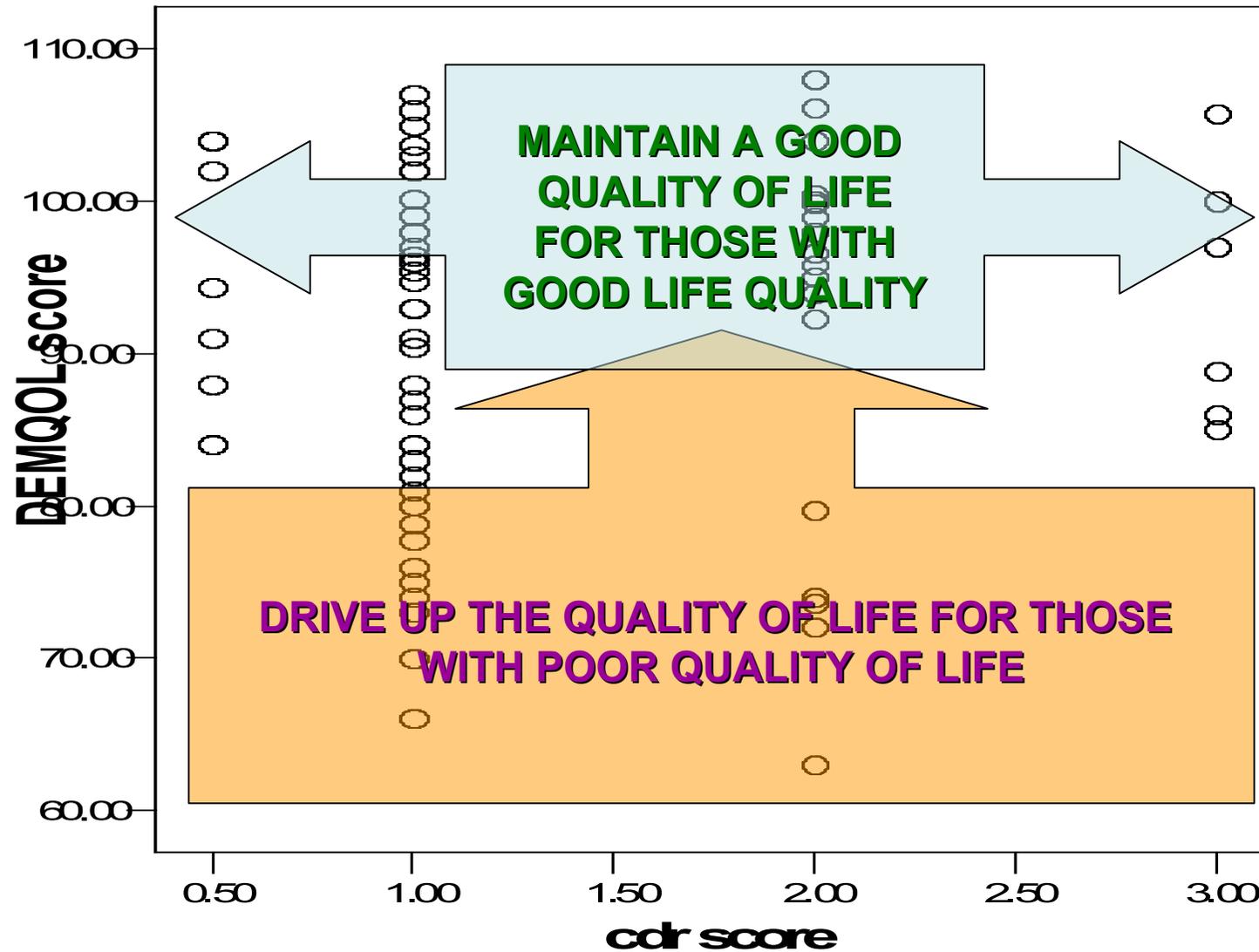
Banerjee et al (2007) JADD

Change in DEMQOL for those below mean (<90)



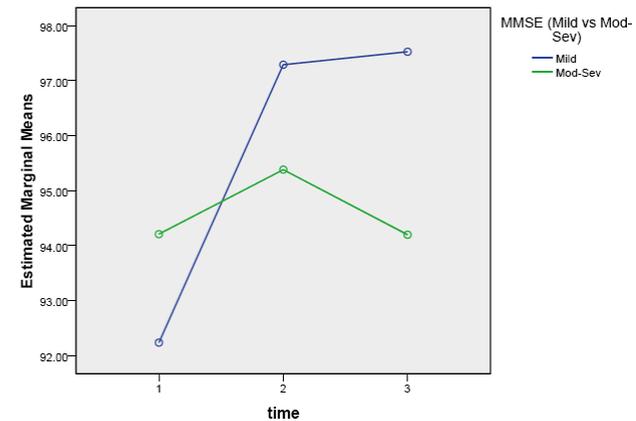
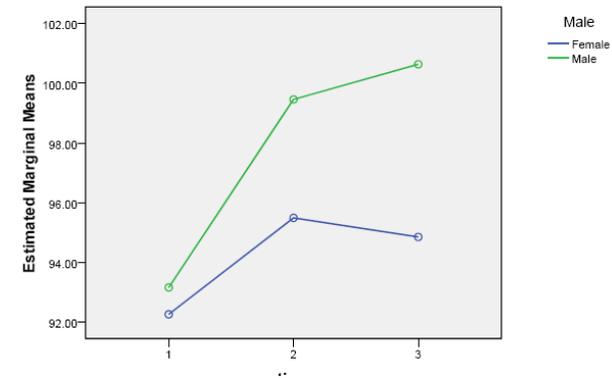
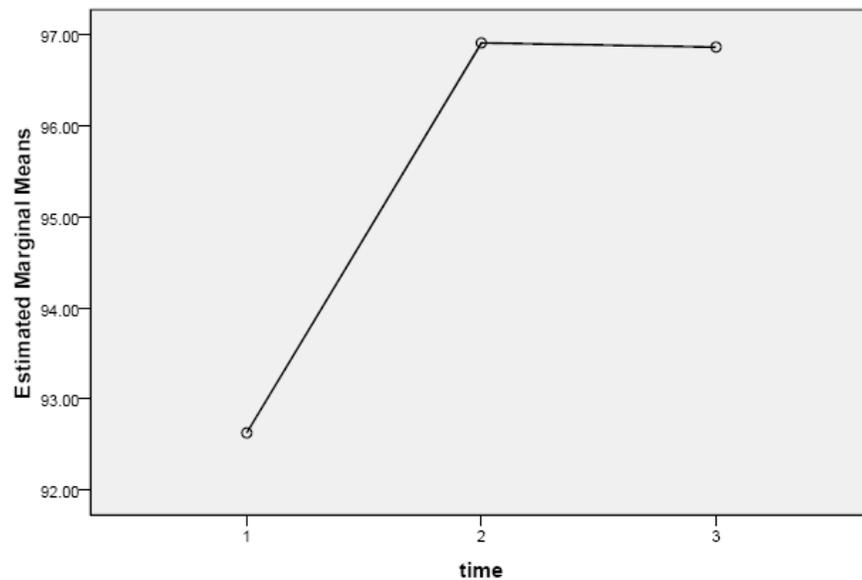
- 6 month DEMQOL change 8.3pt, paired $t=4.99$, $p<0.001$, Cohen's $d = 0.79$
- 12 month DEMQOL change 7.8pt, paired $t=3.88$, $p<0.001$, Cohen's $d = 0.60$

Distribution of DEMQOL scores by CDR score



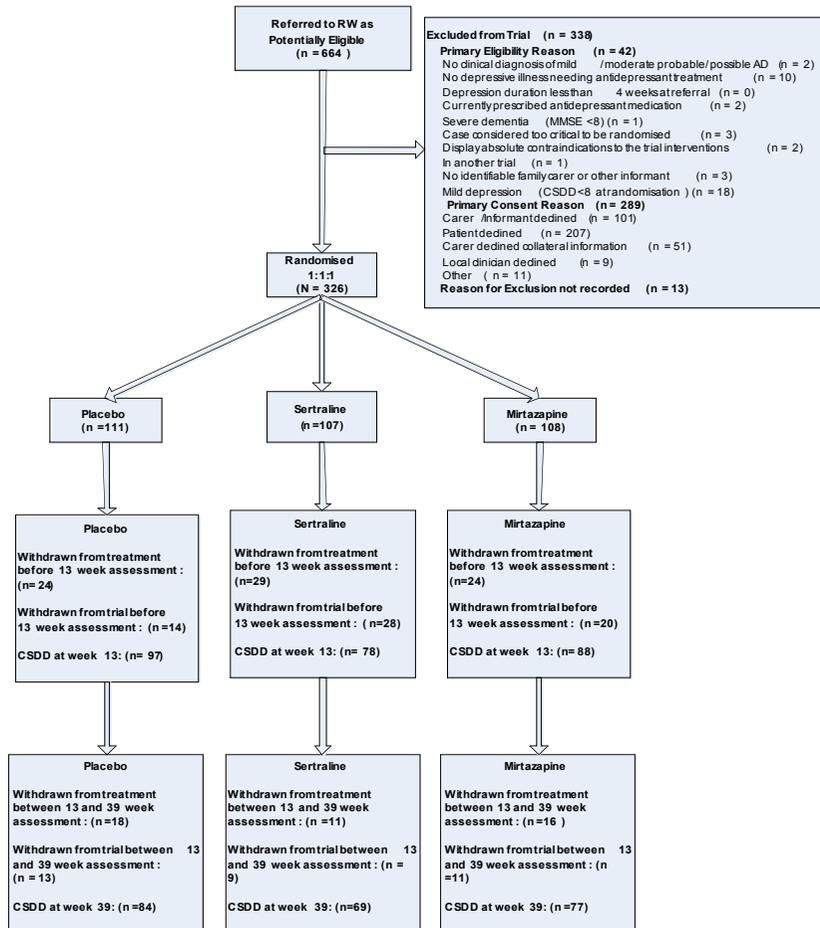
Changes over time in real world clinical practice, DEMQOL scores from the Croydon Memory Service

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

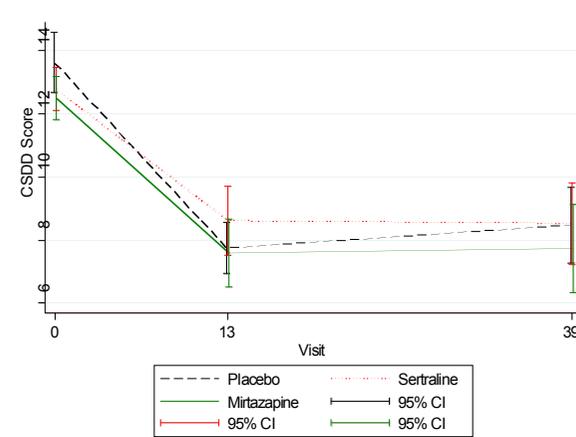


What works?

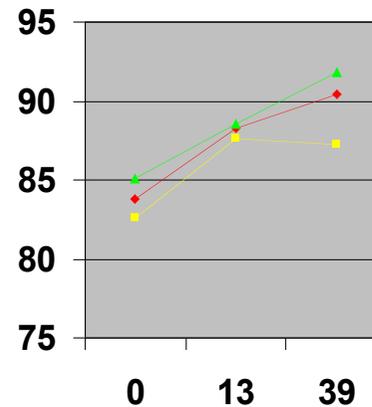
HTA-SADD Trial



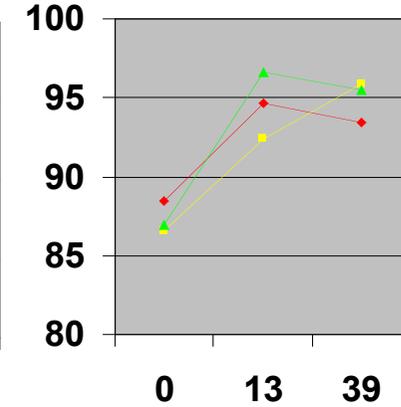
CSDD Score



DEMQOL Score



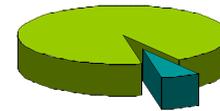
DEMQOL-Proxy Score



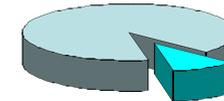
Services for early diagnosis and intervention in dementia for all

- 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
 - Break diagnosis well
 - Provide immediate support and care immediately from diagnosis

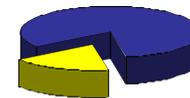
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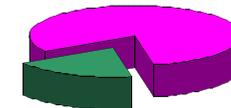
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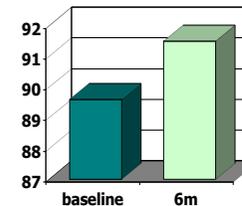
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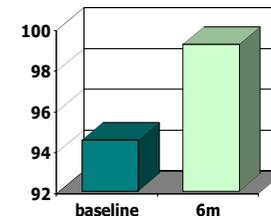
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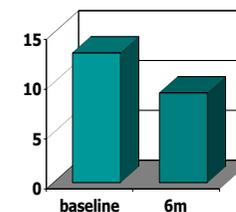
Improvement in self-rated quality of life



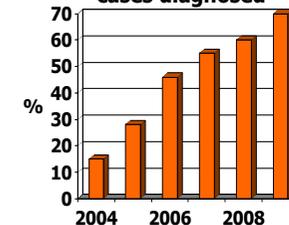
Improvement in carer-rated quality of life

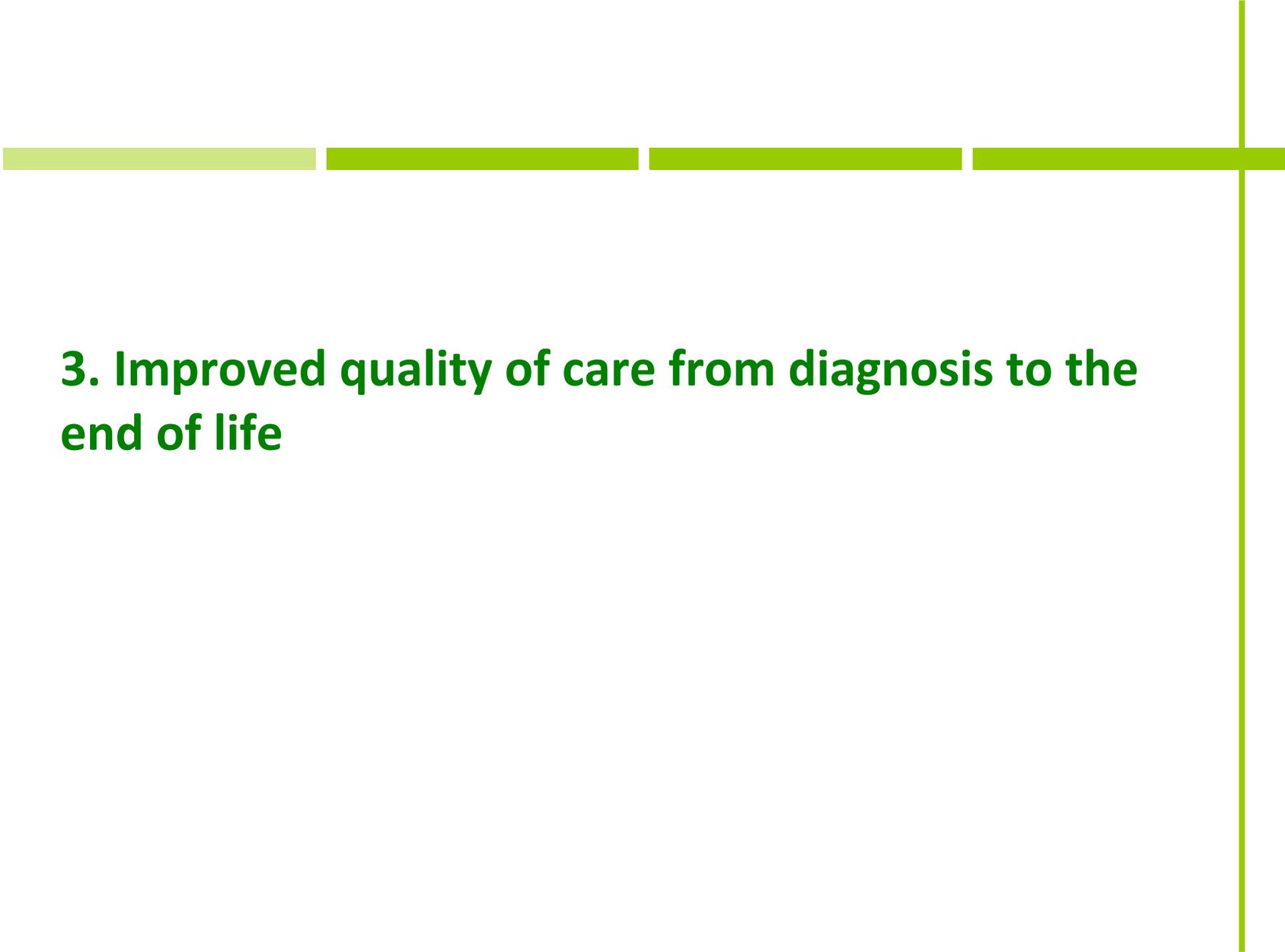


Decrease in behavioral disorder



Proportion of new cases diagnosed





3. Improved quality of care from diagnosis to the end of life

Priorities of people with dementia and carers from the consultation

- O4. Enabling easy access to care, support and advice following diagnosis
 - dementia advisors – not being left alone by services on the journey
- O5. Development of structured peer support and learning networks
 - third sector lead – who knows best?

Theme 3 - Improving quality of care



- O6. Improved community personal support services
 - generic and specialist – collation of data
- O7. Implementing the Carers' Strategy for people with dementia
 - make it work for dementia
- O8. Improved quality of care for dementia in general hospitals
 - clinical leads for dementia, specialist liaison teams – collation of data
- O9. Improved intermediate care for people with dementia
 - change in guidance
- O10. Housing support, related services and telecare
 - watching brief
- O11. Living well with dementia in care homes
 - including review of use of antipsychotic medication in dementia
- O12. Improved end of life care for people with dementia
 - making it work for dementia

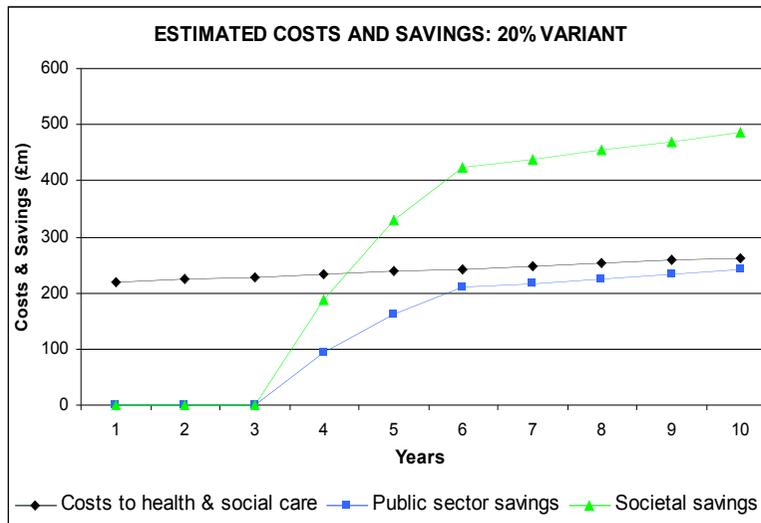
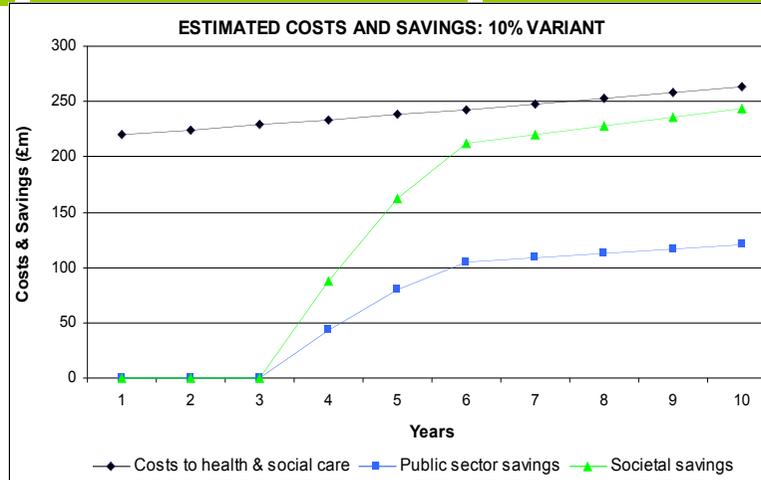


Money

clinical/cost effectiveness

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

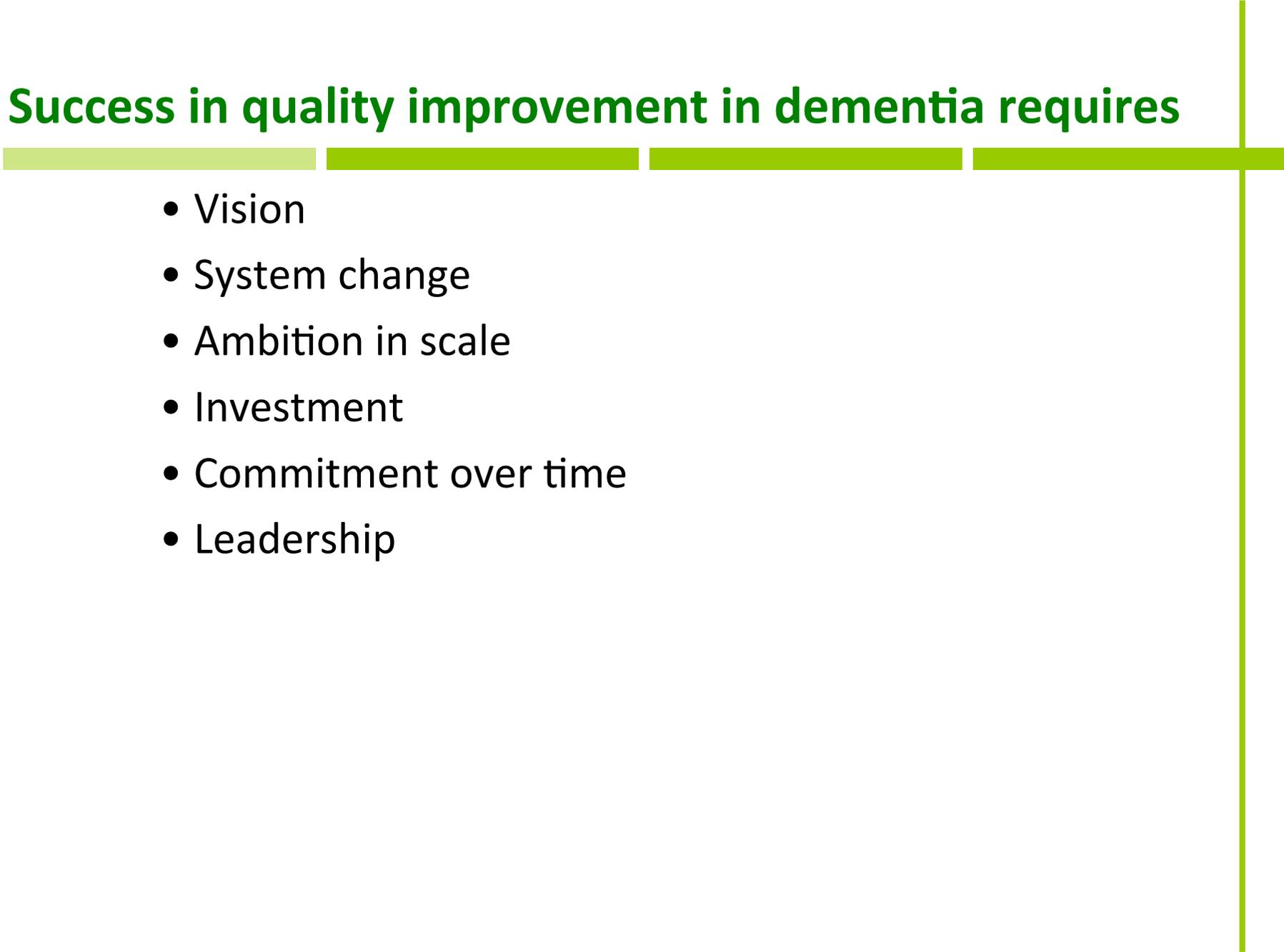
Please ignore – not English - economics

- 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.

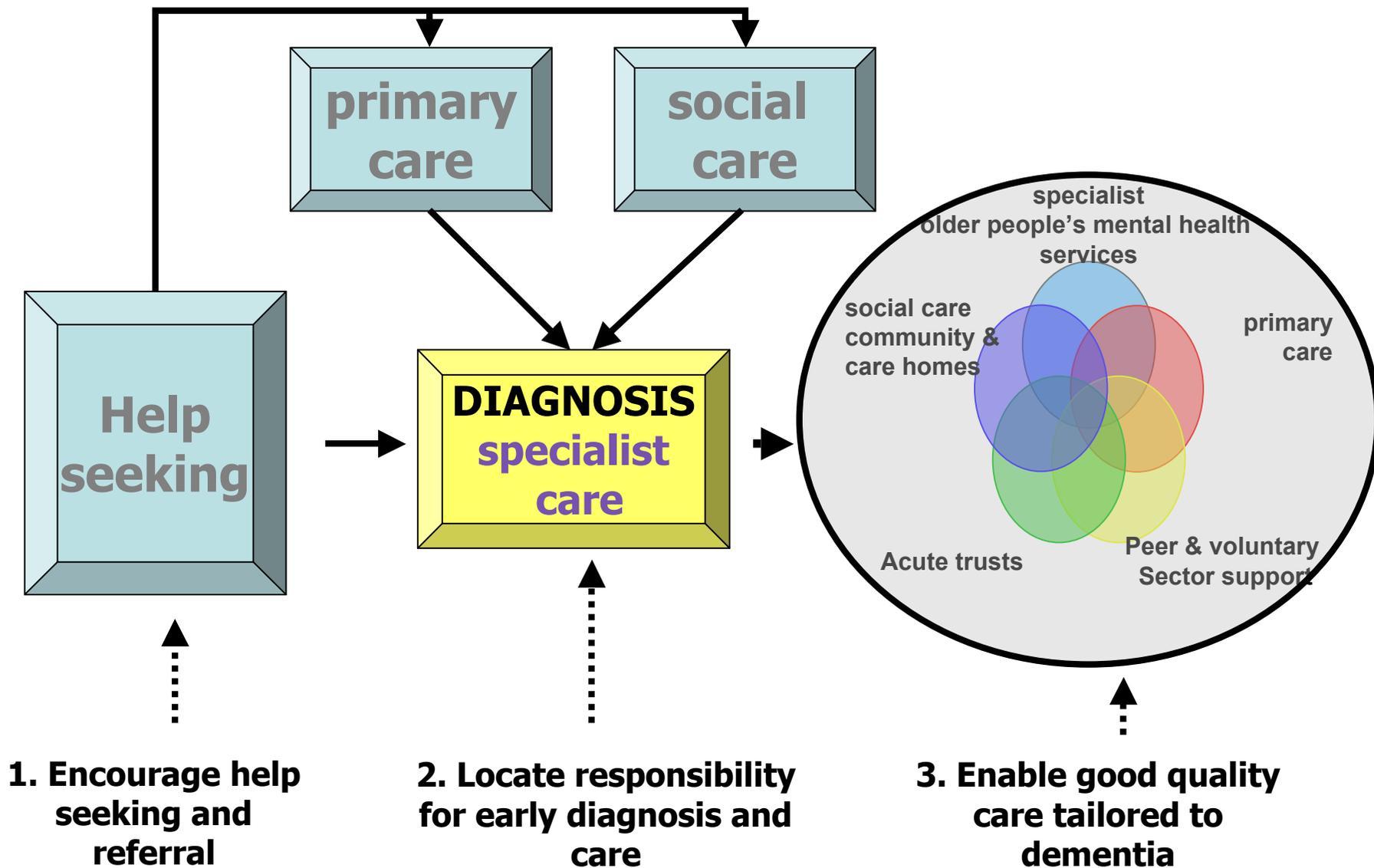
- Needs only:-
 - a modest increase in average quality of life of people with dementia,
 - plus a 10% diversion of people with dementia from residential care, to be cost-effective.
- Banerjee and Wittenberg (2009) IJGP
- The net increase in public expenditure would then, be justified by the expected benefits.

Success in quality improvement in dementia requires



- Vision
- System change
- Ambition in scale
- Investment
- Commitment over time
- Leadership

Dementia care pathway – simple, navigable and commissionable





Thank you and good luck!