MODELLING THE COSTS OF DEMENTIA COSTS

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Outline

- The MODEM project
- Modelling scenarios of dementia care
- Methodological challenges

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MODEM

A comprehensive approach to modelling outcome and costs impacts of interventions for dementia

2014-2018

Improving Dementia Care
ESRC·NIHR

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A collaborative study

LSE (PSSRU)

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- Ann Bowling

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International Longevity Centre-UK

- Sally-Marie Bamford
- Sally Greengross

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What do we know?

- **In future will need to spend much more on the care of people with dementia than we spend today.**
- In England, earlier PSSRU work at LSE led by Raphael Wittenberg projected that by 2022, public expenditure on social care and continuing health care for older people will need to increase by 37%
- Almost half of this is associated with care of people with dementia
- Globally, the WHO suggests that the cost of dementia will double in 20 years
- Life expectancy, prevalence, type and quality of care will affect future funding requirements.

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What are our research questions?

- How many people with dementia will there be between now and 2040?
- What will be the costs and outcomes of their treatment, care and support under present arrangements?
- How do these costs and outcomes vary with characteristics and circumstances of people with dementia and carers?
- How could costs change (in level and distribution) if evidence-based interventions were more widely available and accessed?

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Interventions and costs

- Interventions of interest
  - Prevention (e.g. lifestyle, nutrition, exercise etc.)
  - Treatments (e.g. medications, cognitive stimulation and other therapies)
  - Care and support arrangements (e.g. telecare/tele-health, respite, carer training and support programmes, training for care staff)
- Costs and outcomes
  - All resource impacts (health, social care and other), including resources of people with dementia, families and communities.
  - Quality of life, clinical and lifestyle effects
  - Carer outcomes

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Intervention - e.g. CST

- Intervention
  - Cognitive stimulation therapy for 8 weeks
  - Includes reality orientation, reminiscence therapy) compared to usual care and support.
- Costs and outcomes (8-week follow-up)
  - CST had better outcomes (cognition and QOL), but also marginally higher costs
  - CST looks more cost-effective than usual care
  - Maintenance CST (another 24 weeks) – good QOL and ADL outcomes
  - … also looks cost-effective (not published yet)

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Intervention - e.g. START

- Intervention
  - Individual therapy programme (8 sessions with psychology graduate + manual)
  - Techniques to understand and manage behaviours of person they cared for, change unhelpful thoughts, promote acceptance, improve communication, plan for future, relax, engage in meaningful enjoyable activities.
- Costs and outcomes (8-month & 24-month follow-up)
  - More effective than standard care and no more costly (from NHS and societal perspectives) – at 8m and 24m
  - Cost-effective when looking at costs and outcomes **for carers** – again over both 8m and 24m
  - Reduces care home admission rate for people with dementia over 24m

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Methods

Engage with people with dementia, carers and other stakeholders at all stages.

Project:

- N of people with dementia over the period to 2040
- family or other unpaid support available to them
- costs of services and unpaid support.

Review evidence of effective and cost-effective interventions for people with dementia and carers (incl. on-going studies)

Collect data to cross-walk between measures in studies

Gather experiential evidence from people with dementia, carers

Simulate wider roll-out of evidence-based interventions on outcomes, costs, patterns of expenditure

Empirical models

- Dynamic micro-simulation projection model on disabling consequences of dementia
- Care pathways model of how interventions impact on the use of services, costs and outcomes
- Macro-simulation projection model of long-term care need, costs and outcomes

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What goes into the models?

- Existing models
- Large-scale datasets (CFAS II, ELSA, NCDS)
- Literature review
- Completed and ongoing trials
- Analysis of data on dementia & social participation/ isolation
- ‘Cross walking’ study of 300 people with dementia and their caregivers
- Focus groups with people with mild dementia and caregivers
- Advisory group and user and carer reference group

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Micro-simulation model

- led by Prof. Carol Jagger, Newcastle University
- epidemiological macro-simulation model SIMPOP13 (CFAS I), 65+
  - links multiple diseases with disability
  - projects future disability burden and disability-free life expectancy
- Australian DynoptaSim micro-simulation model, 45+
  - health and functional status
  - potential impact of risk reduction interventions

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Micro-simulation model

- baseline characteristics: socio-demographic, lifestyle and disease (CFAS II & ELSA, 65+) to 2040
- interventions that prevent or delay cognitive and/or functional impairment
- tabulations of expected duration in different health states in presence of dementia, with w/out other diseases and by key characteristics, e.g. gender, age)

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Care pathways model

- led by PSSRU (LSE)
- a coherent model of different interventions and impact on service use, costs and outcomes
- Identify packages of care associated with sets of clinical and other circumstances
- estimate lifetime costs of care for different sets of needs and circumstances given:
  - existing treatment and care pathways
  - alternative care pathways (wider roll-out of interventions)

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Macro-simulation model

PSSRU macro-simulation projection model:

- future numbers of people with dementia
- severity and physical disability (CFAS II)
- long-term care service use
- associated public expenditure
- quality of life

under variant assumptions about:

- trends in mortality rates
- cognitive impairment
- supply of informal care
- patterns of care services
- unit costs of care.

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And finally – a legacy tool

We will develop a publicly available legacy model (and associated media) for others to use.

Commissioners, providers, advocacy groups, individuals and families will be able to access our findings and methods, and make their own projections of needs for care and support, outcomes and costs.

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Scenarios of dementia care

- Study commissioned by the Department of Health from PSSRU in spring 2014 and conducted rapidly over three months
- Study aimed to compare the economic consequences of four dementia care scenarios with current care arrangements in England
- Findings presented at G7 Legacy Event on Dementia held in London in June 2014 and report published for the event

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Research team

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The research team are grateful to many experts for their help, support and comments

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Question: What is the economic case for new dementia care scenarios?

- ***Current care scenario***: Care and support as currently provided in England (***Scenario A***).
- ***No-diagnosis scenario***: Dementia is not diagnosed or treated (***B***).
- ***Diagnosis-only scenario***: Dementia is diagnosed but not treated (***C***).
- ***Improved care scenario***: Dementia is diagnosed, followed by evidence-based, 'improved' care and support (***D***).
- ***Disease-modifying scenario***: Disease-modifying treatments are available to slow progression or delay (***E***).

Knapp et al. *Scenarios of Dementia Care* 2014

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Methods

- Rapid review of available evidence in areas spanned by the scenarios
- Development of aggregate model estimating UK costs and quality of life impacts in 2015
- Development of life-time costs model of costs and QoL for an individual newly diagnosed
- Analyses of data on costs and QoL from a number of recent trials

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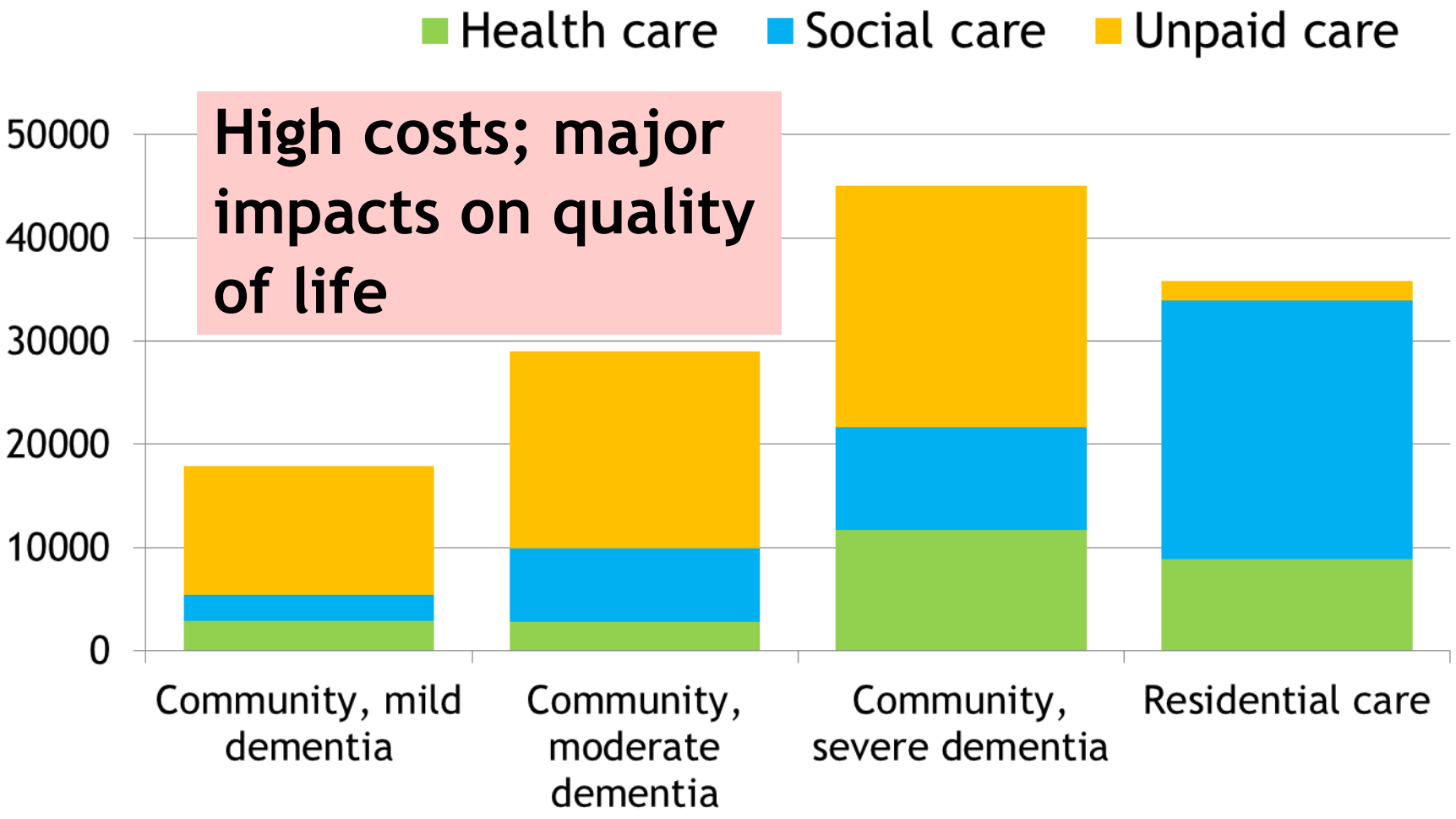
Methods for our models

1. Prevalent dementia population by age & gender
2. Severity of cognitive impairment
3. Place of residence: community or care home
4. Type of care (formal, unpaid, both, neither)
5. Cost & quality of life data from trials (n = 1400)
6. Estimate & compare scenario costs and QALYs

The cost of dementia in England 2015 - per person per year (£, at 2012 prices)



Knapp et al. *Scenarios of Dementia Care* 2014

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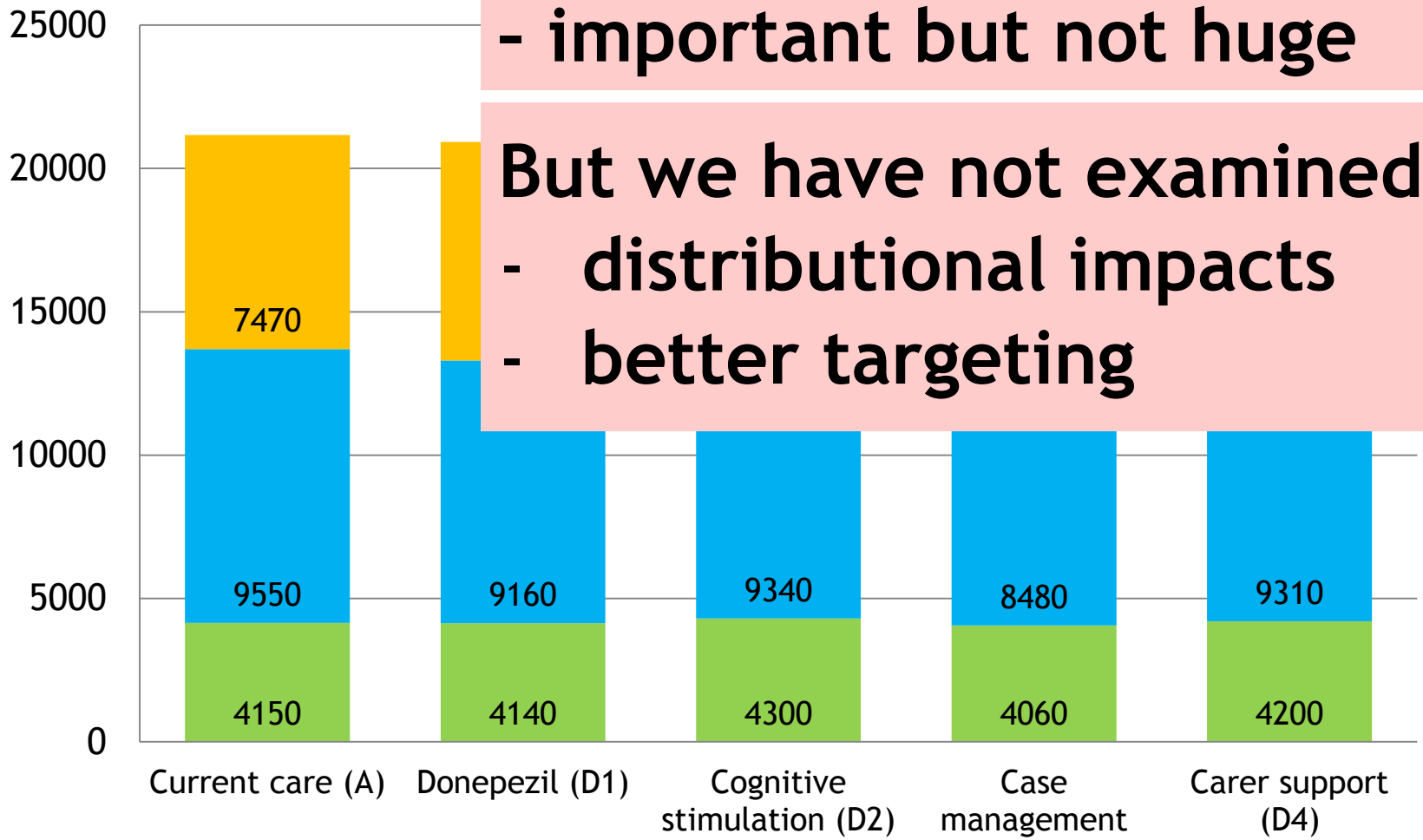
Improving dementia care: modest effects on costs (£ millions, 2012 prices, UK)



Quality of life improvements - important but not huge

But we have not examined:

- distributional impacts
- better targeting

Knapp et al. *Scenarios of Dementia Care* 2014

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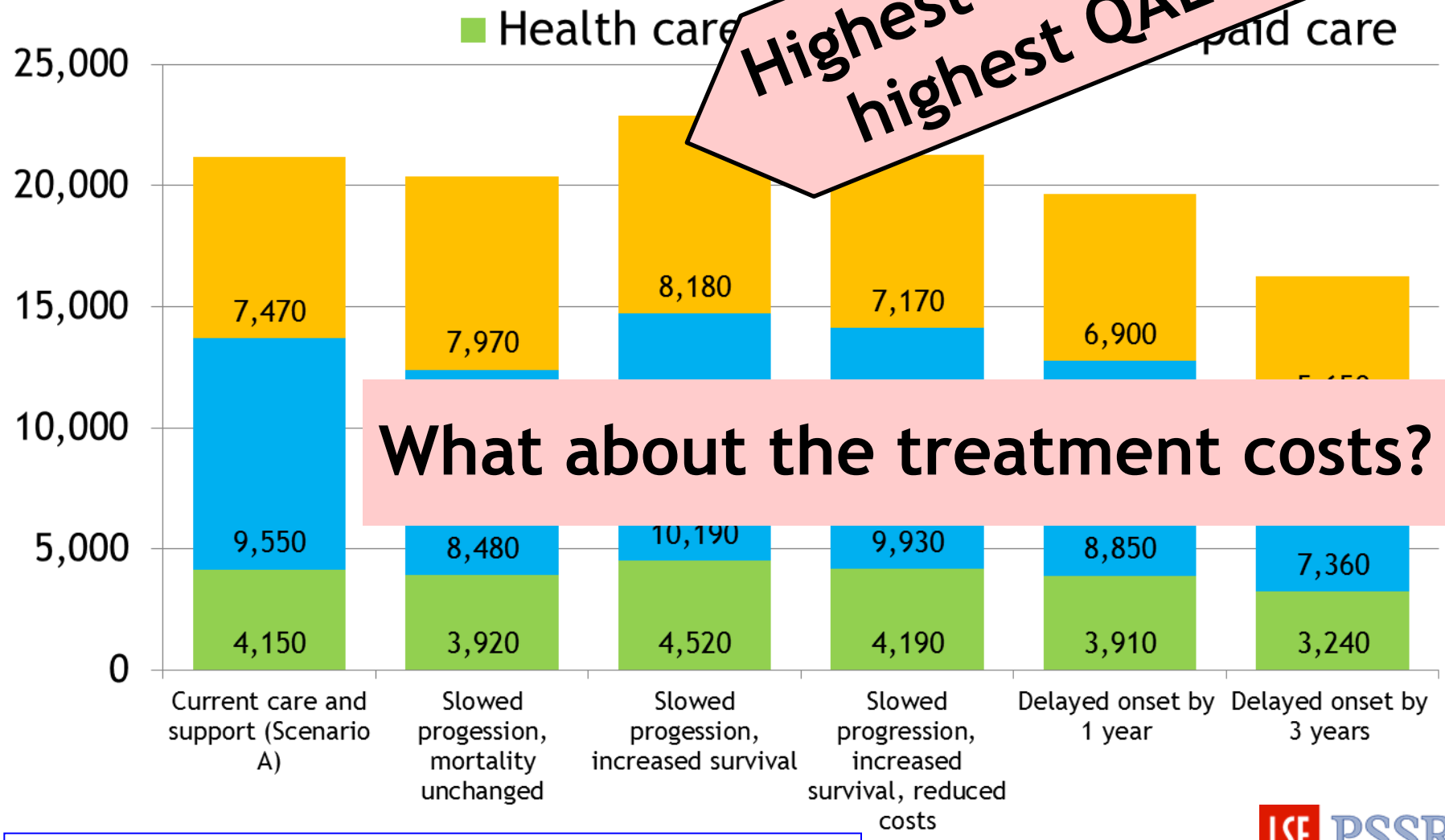
Disease-modification: effects on c
(£ millions, 2012 price

Highest cost … but also highest QALY gain



What about the treatment costs?

Knapp et al. *Scenarios of Dementia Care* 2014

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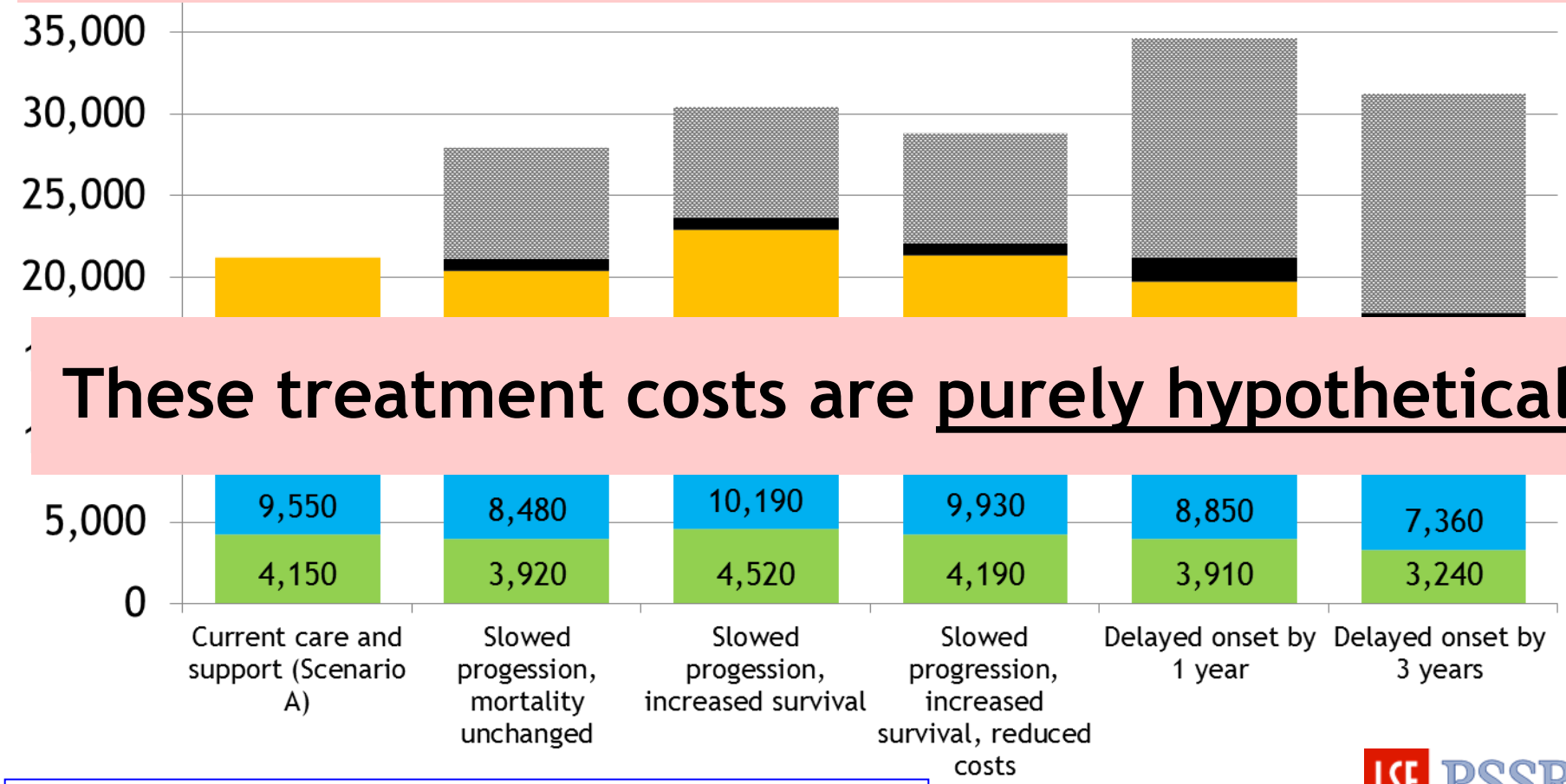
Disease-modification: factoring in the costs of the new treatments

Treatment costs will have a huge influence, depending on price and number treated



These treatment costs are <u>purely hypothetical</u>

Knapp et al. *Scenarios of Dementia Care* 2014

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An economic case for 'better' responses?

- ***Dementia is already costly*** ... and much of that impact falls to family and other unpaid carers.
- ***Dementia will get much more costly***... everywhere, soon.
- ***Known evidence-based 'improvements' will help*** ... to achieve quality of life gains, but costs won't fall much.
- ***Some of those economic gains rely heavily on carers*** ... can they cope with greater responsibilities?
- ***Disease-modifying treatments are needed*** ... to delay onset / slow progression ... to cut costs and improve lives.
- ***We need a two-pronged approach*** ... improve today's care and find tomorrow's cure (treatment breakthroughs).

Key research challenges

- How best to estimate the opportunity costs of unpaid care
- How to estimate the value of lost duration of life and reduced quality of life
- How to combine outcomes for people with dementia and those for unpaid carers

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Further details

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