Dementia:
modelling interventions, costs and outcomes

Evaluation of public policies for sustainable Long-Term Care in Spain Workshop
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Adelina Comas-Herrera
PSSRU
London School of Economics and Political Science
a.comas@lse.ac.uk

Improving Dementia Care
ESRC·NIHR

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Outline

- The MODEM project
- Initial dementia modelling scenarios
- Methodological challenges

A collaborative study

LSE (PSSRU)

- Martin Knapp
- Adelina Comas-Herrera
- Raphael Wittenberg
- Josie Dixon
- Margaret Dangoor
- David McDaid

LSE (Social Policy Dept)

- Mauricio Avendano
- Emily Grundy

Southampton University

- Ann Bowling

Newcastle University

- Carol Jagger

Sussex University

- Sube Banerjee

International Longevity Centre-UK

- Sally-Marie Bamford
- Sally Greengross

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.

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?

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

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)

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

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

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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

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

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)

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)

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
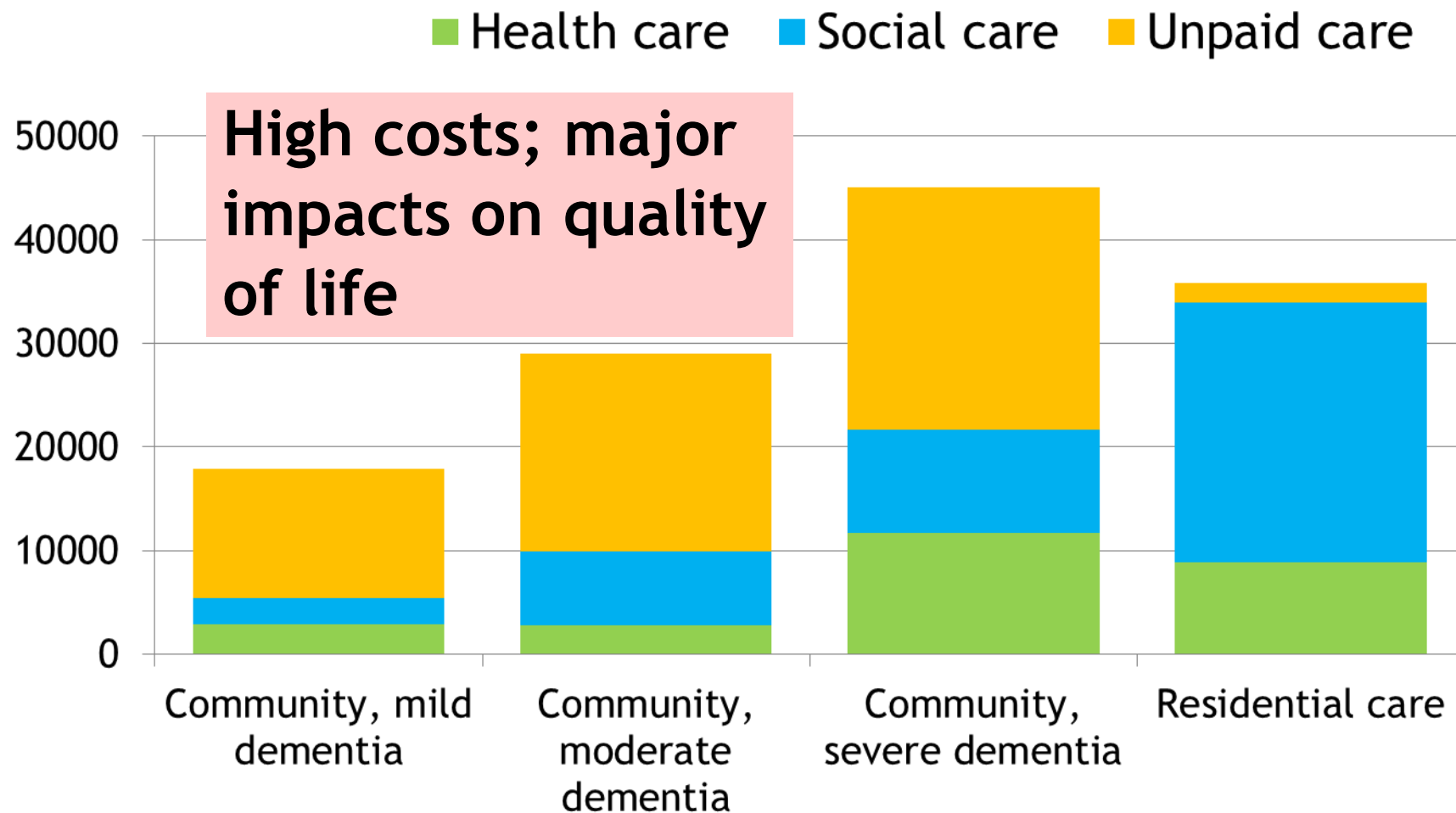- unit costs of care.

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.

Initial Dementia Scenarios Modelling

- Estimation of the costs of dementia for the UK in 2015, given different scenarios:
- If care remains as now
- If cost-effective interventions were widely adopted
- If there was a new disease-modifying treatment
- Work funded by the Department of Health, presented at the *G8's First Global Dementia Legacy Event on Finance and Social Impact Investment in Dementia*

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

■ Health care   ■ Social care   ■ Unpaid care

High costs; major impacts on quality of life

Knapp et al. *Scenarios of Dementia Care* 2014

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

Quality of life improvements – important but not huge

But we have not examined:
- **distributional impacts**
- **better targeting**

Legend: Unp...

Scenario	Green	Blue	Orange
Current care (A)	4150	9550	7470
Donepezil (D1)	4140	9160	
Cognitive stimulation (D2)	4300	9340	
Case management (D3)	4060	8480	
Carer support (D4)	4200	9310	

Y-axis: 0, 5000, 10000, 15000, 20000, 25000

Knapp et al. *Scenarios of Dementia Care* 2014

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Disease-modification: effects on (£ millions, 2012 prices)

Highest cost … but also highest QALY gain
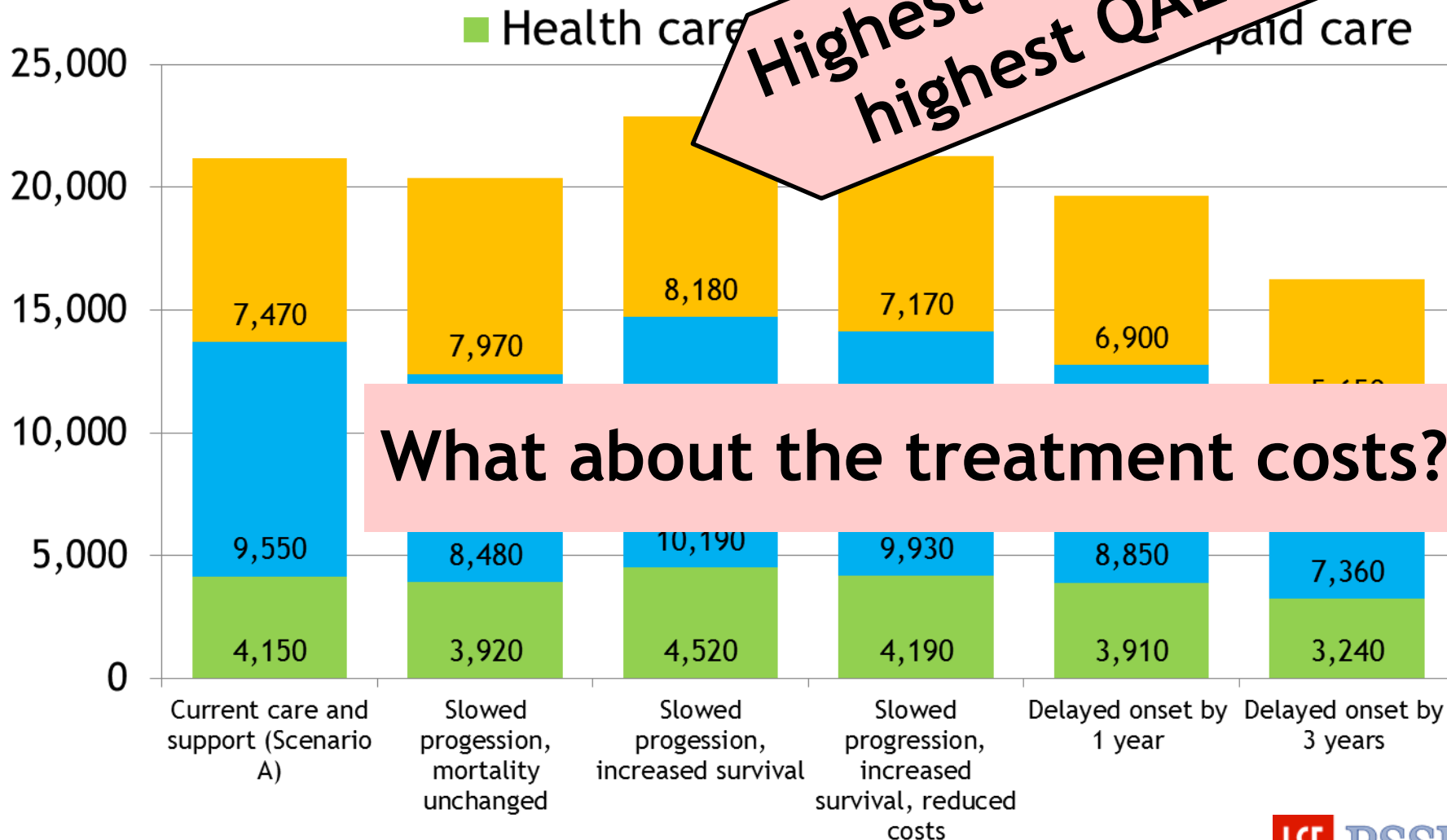
What about the treatment costs?

Legend: ■ Health care ... paid care

	Current care and support (Scenario A)	Slowed progression, mortality unchanged	Slowed progression, increased survival	Slowed progression, increased survival, reduced costs	Delayed onset by 1 year	Delayed onset by 3 years
Yellow (top)	7,470	7,970	8,180	7,170	6,900	5,650
Blue (middle)	9,550	8,480	10,190	9,930	8,850	7,360
Green (bottom)	4,150	3,920	4,520	4,190	3,910	3,240

Knapp et al. *Scenarios of Dementia Care* 2014
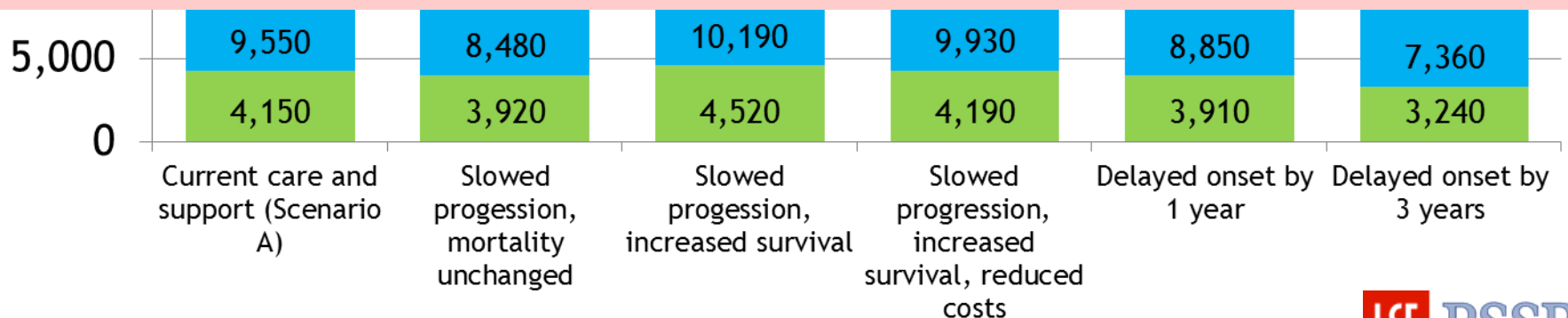
Disease-modification: factoring in the costs of the new treatments

Treatment costs will have a huge influence, depending on price and number treated
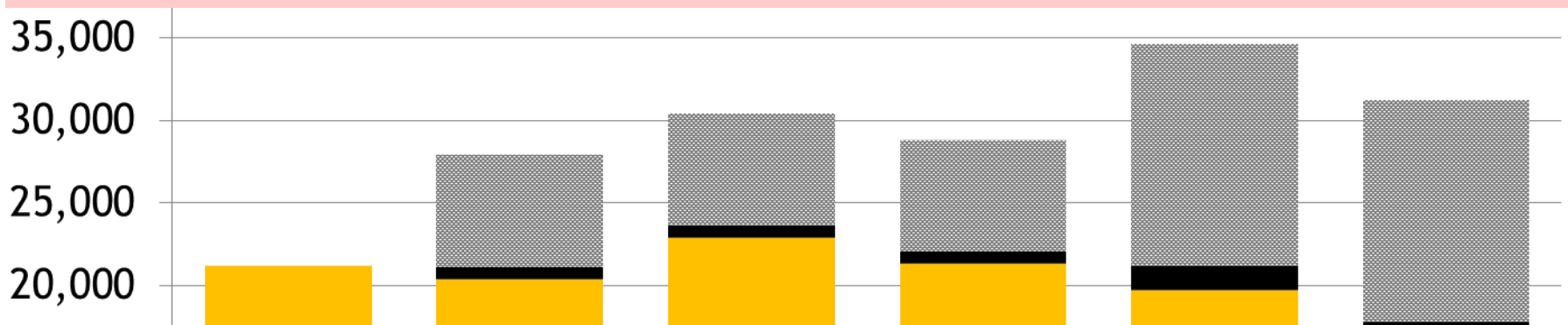
These treatment costs are <u>purely hypothetical</u>

	Current care and support (Scenario A)	Slowed progession, mortality unchanged	Slowed progession, increased survival	Slowed progression, increased survival, reduced costs	Delayed onset by 1 year	Delayed onset by 3 years
(blue)	9,550	8,480	10,190	9,930	8,850	7,360
(green)	4,150	3,920	4,520	4,190	3,910	3,240

Knapp et al. *Scenarios of Dementia Care* 2014

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Are we facing the 'perfect storm'?

- Demography is rapidly pushing up *prevalence …*

- … and creating smaller *families* …

- … which are geographically more *dispersed.*

- *Communities* may be less supportive(?)

- Hence huge (and long-term?) *economic pressures* on individuals and governments

- Hardening *attitudes* towards mental illness

- … While decision-makers retreat into their *silos*, in pursuit of immediate *cashable savings*.

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 <u>care</u> and find <u>tomorrow's cure</u> (treatment breakthroughs).

Key research challenges:

- What happens to outcomes and costs when you "stack-up" interventions?

- Outcomes: combining the outcomes of people with dementia and those of carers

- Understanding better the impact of changes in severity of dementia and quality of life

Further details

Scenarios of dementia care:

What are the impacts on cost and quality of life?

Martin Knapp, Adelina Comas-Herrera,
Raphael Wittenberg, Bo Hu, Derek King,
Amritpal Rehill and Bayo Adelaja

Personal Social Services Research Unit,
London School of Economics and Political Science

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PSSROL
Personal Social Services Research Unit

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Thank you.

a.comas@lse.ac.uk

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