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Making strides in dementia treatment, care, support and awareness

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All views expressed in this presentation are those of the presenter, and are not necessarily those of the DH or NIHR.

There are no conflicts of interest to report relevant to this presentation.

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Structure of my talk

A. New challenges?

B. New responses?

C. New scenarios?

D. New directions?

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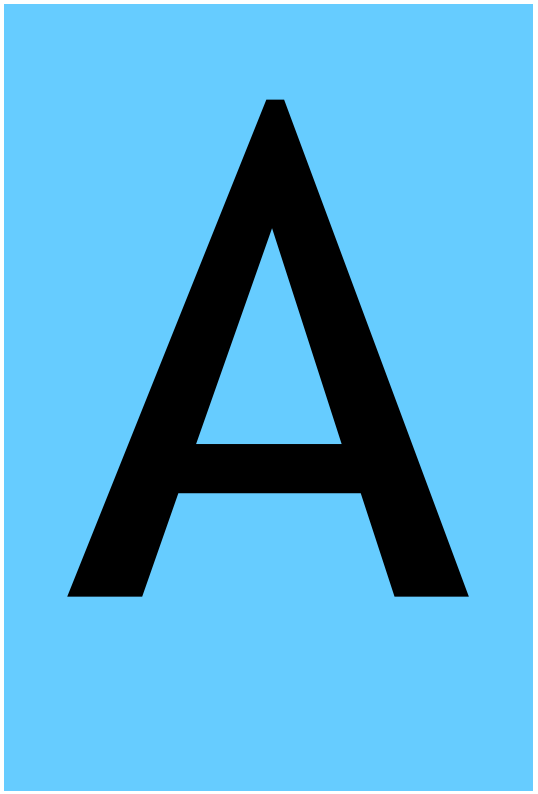

New challenges?

Huge changes since 1974

Number of people with dementia UK	c. 350,000 in 1974	c. 816,000 in 2014
Percentage of care home residents UK	11% 'severely confused' in 1970	17% 'severe dementia' in 2014
Papers in Medline with keyword 'Alzheimer'	42 in 1975	75,646 yesterday

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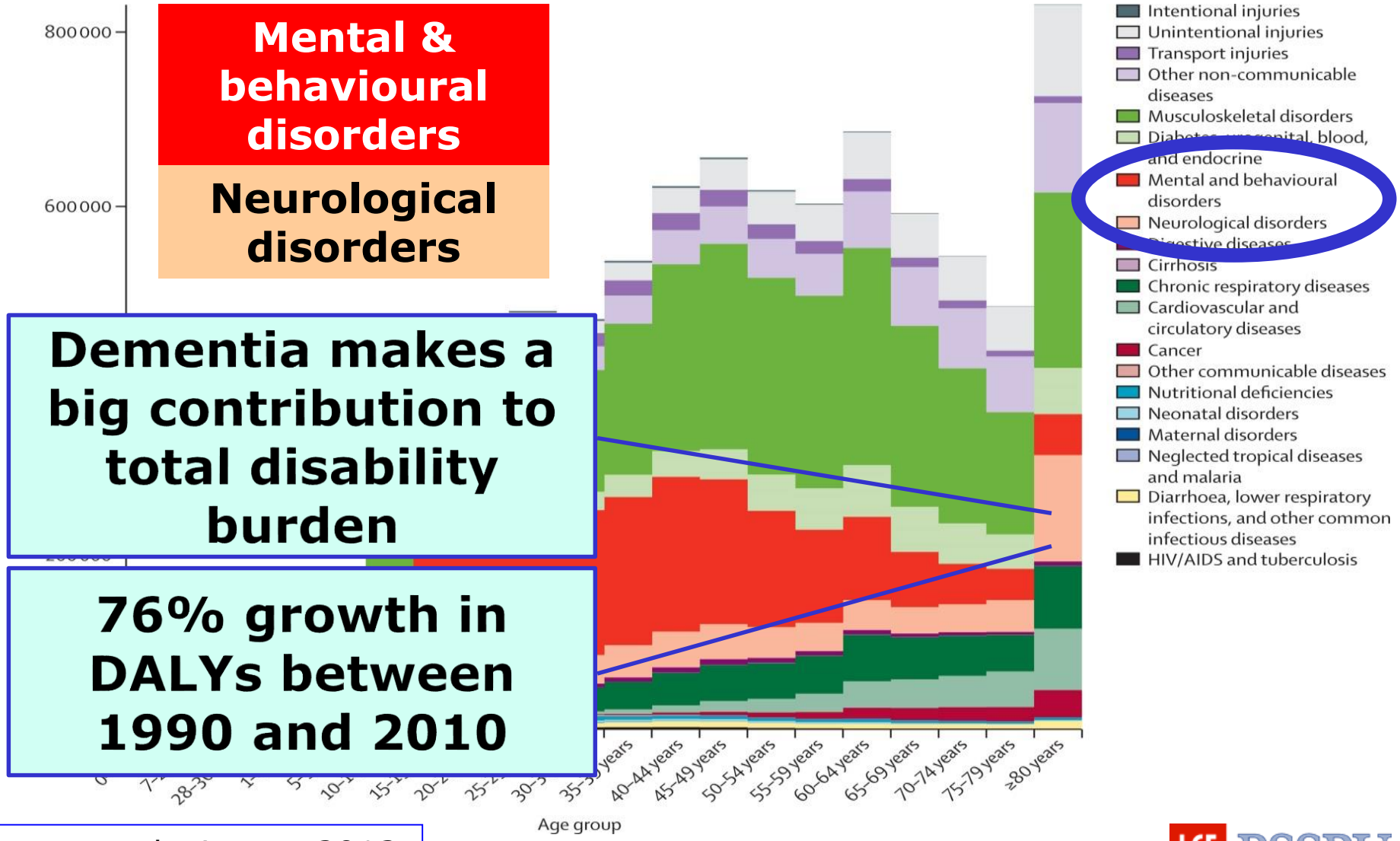
Years lived with disability by cause and age, UK in 2010



Dementia makes a big contribution to total disability burden

76% growth in DALYs between 1990 and 2010

Murray et al , *Lancet* 2013

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Huge challenges for my granddaughter - and for each of us

- 2 out of 5 girls born today will reach age 100 (ONS projections), and 72% of women aged 95+ have dementia (*Dementia UK 2014*) …
- … So (if prevalence rates stay the same), there is c.30% chance my new granddaughter will be living with dementia in 2114

- Dementia is **not rare**: almost all of us have a relative with dementia
- There is **no cure**. Nor any simple care solution.
- Responsibilities **straddle** health, social care, housing, social welfare
- … but **unpaid carers** are the bedrock of dementia care
- **Outcomes** are hard to define and measure, particularly self-report
- And dementia **costs** a huge amount.

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And total prevalence will continue to grow

"A global epidemic". "An emergency in slow motion". "A demographic time-bomb"

Although the CFAS II study – and some others – suggest that the prevalence <u>rate</u> might be slowing

With big consequences for expenditure:

- for healthcare and long-term care systems;

- for individuals with dementia and their families.

Alzheimer's Disease International website; Matthews et al, *Lancet* 2013

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MODEM: a projections study (2014-18)

- How many people with dementia 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 individual characteristics and circumstances?
- How could costs and cost-effectiveness change if better interventions were more widely available and accessed?

Methods – data-heavy modelling:

- Micro-simulation, macro-simulation, care pathways

Team: Martin Knapp, Mauricio Avendano, Sally-Marie Bamford, Sube Banerjee, Ann Bowling, Adelina Comas, Margaret Dangoor, Josie Dixon, Emily Grundy, Bo Hu, Carol Jagger, Maria Karagiannidou, Derek King, Daniel Lombard, David McDaid, Jitka Pikhartova, Amritpal Rehill, Raphael Wittenberg,

Improving Dementia Care
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B New responses?

New responses: what works?

- Prevention
- Screening
- Carer support
- Staff skills training
- Treatments
- Home-based care
- Case management
- Attitudes

What is the evidence on 'new responses' in these areas?

Evidence here drawn from recent/imminent studies:

- Knapp, Black, Dixon et al. *Improvements in Dementia Care and Support since 2009*, forthcoming (PSSRU/PIRU/SSCR).
- Many recent trials & other studies (see later references)
- Knapp, Iemmi, Romeo (2013) Dementia care costs and outcomes: systematic review, *Int J Geriatric Psychiatry*.

Prevention

Population-attributable risk (PAR) of Alzheimer's disease:

- Diabetes
- Midlife hypertension
- Midlife obesity
- Physical inactivity
- Depression
- Smoking
- Low educational attainment

Combined worldwide PAR, adjusting for interdependence, was 28%

"Around a third of AD cases worldwide might be attributable to potentially modifiable risk factors"

Norton et al *Lancet Neurology* 2014

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Prevention - tailored exercise programme

Individuals with dementia and their carers tried a tailored walking regimen (20-30 mins, at least 5 times per week).

RCT, n= 131 dyads. Mixed findings:

- No improvement in behavioural or psychological symptoms of dementia
- But reduction in carer burden (Zarit)
- Probably cost-effective from health-social care and societal perspectives

Lowery et al *IJGP* 2014; Rehill et al, paper in preparation

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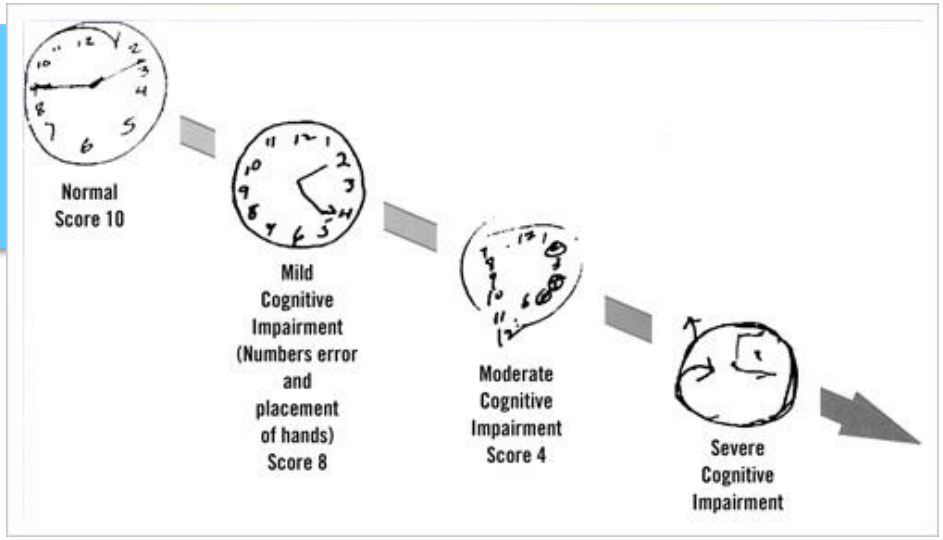
Screening



Big debate about whether population screening for dementia is sensible.

- Raise unrealistic expectations among individuals about what can be done?
- Divert attention and resources away from those who are already diagnosed?
- **But** don't individuals have the right to know and to plan?
- And isn't there now promising evidence on interventions?

Dixon et al *IJGP* 2014

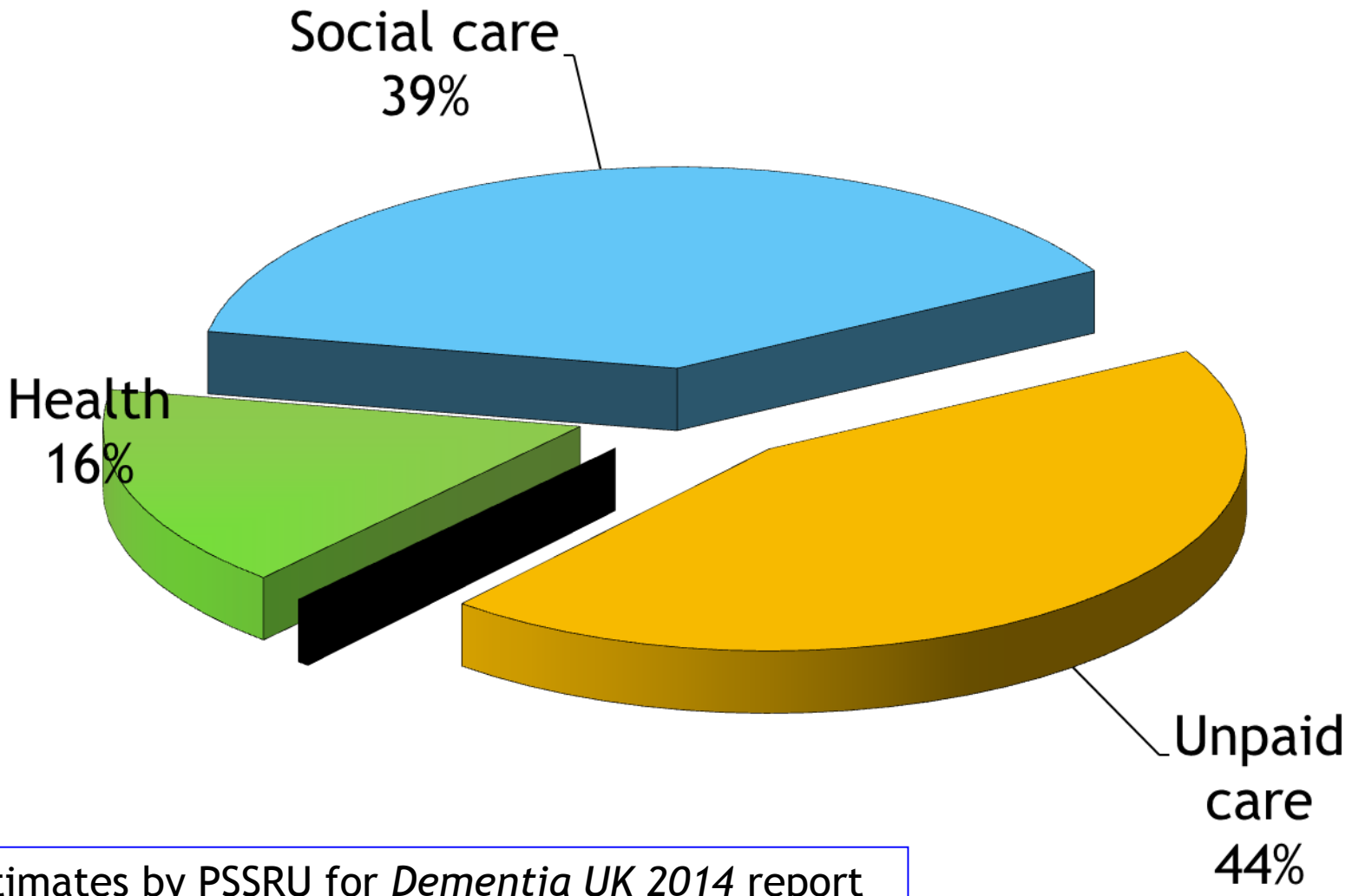
A one-off dementia screen at age 75 followed by post-diagnostic support (*model*):

- 2152 of 3514 people diagnosed would never have received a diagnosis
- Screening can be cost-effective, especially as better care and treatments become available

Carer support

- ‘Research shows that carers of people with dementia experience greater strain and distress than carers of other older people. We want to see better support for carers’ (*Prime Minister’s Challenge on Dementia*, 2012)
- Unpaid carers – the unsung heroes of dementia care
- High out-of-pocket and imputed costs → → →

Cost of dementia in the UK 2014: percentage contributions



Estimates by PSSRU for *Dementia UK 2014* report to be launched by the Alzheimer's Society 2014

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Carer support

- 'Research shows that carers of people with dementia experience greater strain and distress than carers of other older people. We want to see better support for carers' (*Prime Minister's Challenge on Dementia*, 2012)
- Unpaid carers – the unsung heroes of dementia care
- High out-of-pocket and imputed costs …
- … and these costs will grow as prevalence increases, and as health and social care budgets get stretched.
- Many carers experience a lot of stress
- So, what works?

START: a manual-based coping strategy

Individual programme (8 sessions over 8-14 weeks, delivered by psychology graduates + manual); carers given techniques to:

- understand behaviours of person they care for
- manage behaviour
- change unhelpful thoughts
- promote acceptance
- improve communication
- plan for the future
- relax
- engage in meaningful, enjoyable activities.

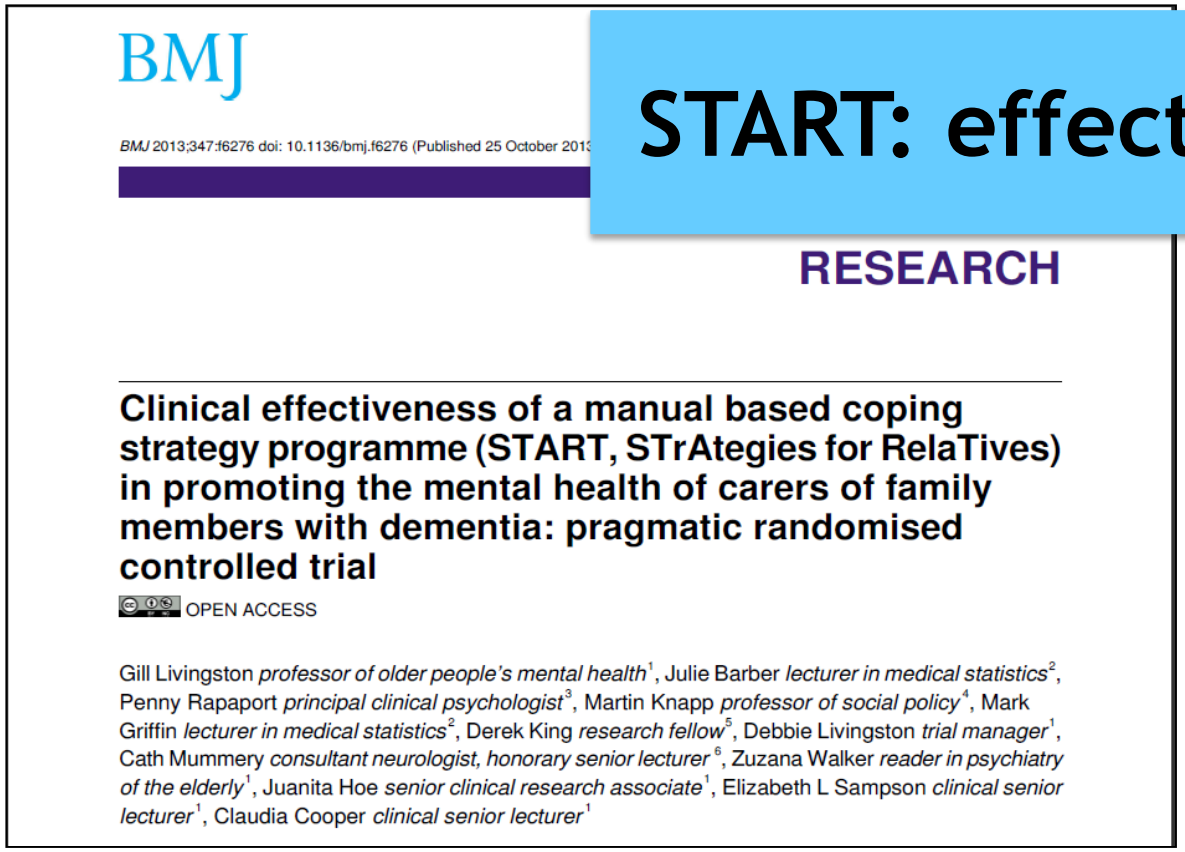
Pragmatic, multicentre RCT – START vs usual support.

n=260 family carers of people with dementia, North London area.

Analyses 8 & 24 months after end of intervention

Livingston et al *BMJ* 2013; Knapp et al *BMJ* 2013; Livingston et al *submitted*

START: effectiveness at 8m



BMJ

BMJ 2013;347:f6276 doi: 10.1136/bmj.f6276 (Published 25 October 201

RESEARCH

Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial

OPEN ACCESS

Gill Livingston *professor of older people's mental health*[1], Julie Barber *lecturer in medical statistics*[2], Penny Rapaport *principal clinical psychologist*[3], Martin Knapp *professor of social policy*[4], Mark Griffin *lecturer in medical statistics*[2], Derek King *research fellow*[5], Debbie Livingston *trial manager*[1], Cath Mummery *consultant neurologist, honorary senior lecturer*[6], Zuzana Walker *reader in psychiatry of the elderly*[1], Juanita Hoe *senior clinical research associate*[1], Elizabeth L Sampson *clinical senior lecturer*[1], Claudia Cooper *clinical senior lecturer*[1]

At 24m – but awaiting review – these **same effects were maintained**.

Plus **QOL gains** for people with dementia.

Carers with *usual support* were 4 times more likely to have **clinically significant depression** than carers with the *START intervention*; HADS-total = 2.10 (95% CI 0.51 to 3.75).

Small incremental **QALY gain** for START group; mean 0.042 (95% CI 0.015 to 0.071).

Livingston et al *BMJ* 2013; Livingston et al *submitted*

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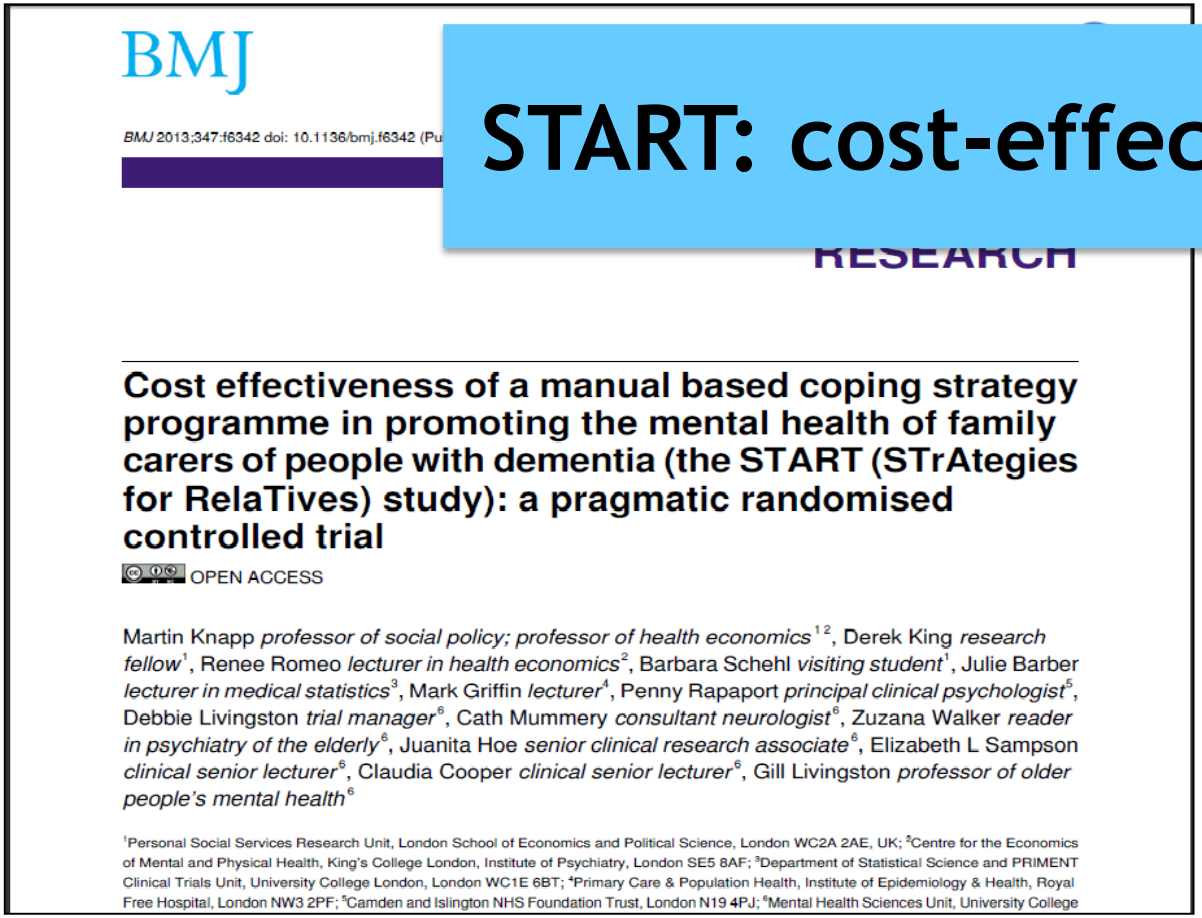
START: cost-effectiveness at 8m



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Cost effectiveness of a manual based coping strategy programme in promoting the mental health of family carers of people with dementia (the START (STrAtegies for RelaTives) study): a pragmatic randomised controlled trial

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[1]Personal Social Services Research Unit, London School of Economics and Political Science, London WC2A 2AE, UK; [2]Centre for the Economics of Mental and Physical Health, King's College London, Institute of Psychiatry, London SE5 8AF; [3]Department of Statistical Science and PRIMENT Clinical Trials Unit, University College London, London WC1E 6BT; [4]Primary Care & Population Health, Institute of Epidemiology & Health, Royal Free Hospital, London NW3 2PF; [5]Camden and Islington NHS Foundation Trust, London N19 4PJ; [6]Mental Health Sciences Unit, University College

At 24m – but awaiting review – START **continued to be cost-effective**, now looking at both carer and patient costs & outcomes.

Carers getting START had slightly but **not significantly higher costs** (£252; 95% CI -28 to +565), adjusting for baseline.

Mean ICERs: £118 per unit change on **HADS-total**; and

£6000 per **QALY** … both measuring carer costs only.

Knapp et al *BMJ* 2013; Livingston et al *submitted*

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Staff skills, training & turnover

The care workforce needs to be skilled in supporting people with dementia. But in England …

- <1% of workers at establishments providing services to people with dementia have **formal dementia qualifications**
- c.33% have received **dementia training** (short courses not leading to qualifications)
- Compared to other parts of the social care workforce, the dementia workforce is more likely to be **female**, **part-time**, employed by agencies, and **less qualified**.
- **Staff turnover** for care workers working with older people with dementia is 31% annually.

HSCIC collections; Hussein & Manthorpe *Ageing & Mental Health* 2012

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Cognitive stimulation therapy (CST)

CST is a group intervention in care homes & day centres for people with mild-to-moderate dementia: themed activities to stimulate cognitive function.

Effective and cost-effective if delivered bi-weekly over 7 weeks.

Maintenance CST (weekly for 24 weeks) improves QOL; in combination with ACHEI meds it improves cognition.

Also cost-effective over 24 weeks, especially with ACHEIs.

BJPsych The British Journal of Psychiatry (2014) 204, 454–461. doi: 10.1192/bjp.bp.113.137414

Maintenance cognitive stimulation therapy for dementia: single-blind, multicentre, pragmatic randomised controlled trial

Martin Orrell, Elisa Aguirre, Aimee Spector, Zoe Hoare, Robert T. Woods, Amy Streater, Helen Donovan, Juanita Hoe, Martin Knapp, Christopher Whitaker and Ian Russell

Background
There is good evidence for the benefits of short-term cognitive stimulation therapy for dementia but little is known about possible long-term effects.

Aims
To evaluate the effectiveness of maintenance cognitive stimulation therapy (CST) for people with dementia in a single-blind, pragmatic randomised controlled trial including a substudy with participants taking acetylcholinesterase inhibitors (AChEIs).

Method
The participants were 236 people with dementia from 9 care homes and 9 community services. Prior to randomisation all participants received the 7-week, 14-session CST programme. The intervention group received the weekly maintenance CST group programme for 24 weeks. The control group received usual care. Primary outcomes were cognition and quality of life (clinical trial registration: ISRCTN26286067).

Results
For the intervention group at the 6-month primary end-point there were significant benefits for self-rated quality of life (Quality of Life in Alzheimer's Disease (QoL-AD) $P = 0.03$). At 3 months there were improvements for proxy-rated quality of life (QoL-AD $P = 0.01$, Dementia Quality of Life scale (DEMQOL) $P = 0.03$) and activities of daily living ($P = 0.04$). The intervention subgroup taking AChEIs showed cognitive benefits (on the Mini-Mental State Examination) at 3 ($P = 0.03$) and 6 months ($P = 0.03$).

Conclusions
Continuing CST improves quality of life; and improves cognition for those taking AChEIs.

Declaration of interest
Royalties from the sale of the *Making a Difference* manuals are paid to the Dementia Services Development Centre, Bangor University.

There is good evidence for the benefits of cognitive stimulation for people with dementia.[1] A recent Cochrane review showed that cognitive stimulation improved both cognition and quality of life.[2] The review concluded that the benefits of cognitive stimulation enhanced those of medication, and that it was effective whether or not acetylcholinesterase inhibitors (AChEIs) were prescribed.[2] The 2011 World Alzheimer report concluded 'there is strong evidence to support cognitive stimulation programmes and these interventions should therefore be routinely offered'.[3] Cognitive stimulation is a psychological intervention for dementia that targets cognitive and social functioning and is designed to enhance general cognitive abilities. Cognitive stimulation therapy (CST) is a well-defined evidence-based version of cognitive stimulation that is standardised, including two training manuals and a DVD.[4] Cognitive stimulation therapy was developed following review of a related approach known as reality orientation[5] and evaluated CST in a pilot trial,[6] followed by a full trial,[4] and developed a manual[7] and a training DVD. It is now used widely across the UK and in several other countries. A pilot study of maintenance CST that continued for an extra 16 weekly sessions beyond the standard 7-week (14-session) CST programme[8] found a significant improvement in cognitive function compared with CST alone. The Cochrane review found no link between duration or frequency of the programme and degree of improvement.[2] Some studies have continued cognitive stimulation for 6 months or more,[9,10] but there is little evidence about how far potential benefits may continue after sessions end. The Cochrane review suggested that after the sessions finished the effects on cognition were evident for at most 3 months;[2] and another study found no continuing effects at 10 months.[11] Our trial aimed to evaluate the effectiveness of maintenance CST in improving cognition and quality of life in people with dementia who have completed the standard CST programme. Hence, the intervention group would continue with maintenance CST, whereas the control group would have standard CST only, followed by treatment as usual (TAU).[12] In addition, a substudy focused on the effects of maintenance CST on people with dementia taking AChEIs.

Method

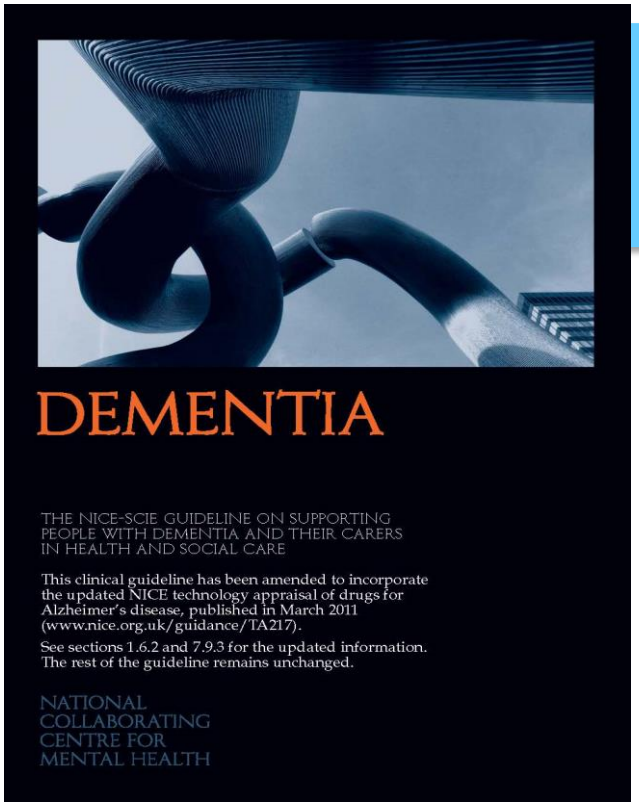
Study design

This was a single-blind, multicentre, pragmatic randomised controlled trial (RCT) comparing maintenance CST groups after completing standard CST *v.* standard CST only followed by TAU.[13] There was no modification in design or eligibility criteria from the study protocol (full details available in Aguirre *et al*[12]). The clinical trial registration number is ISRCTN26286067.

Participants

Potential centres were screened for eligibility to determine whether there were sufficient numbers of potential participants with dementia, using the inclusion criteria flow chart. Participants all met DSM-IV criteria for dementia[14] using the diagnostic algorithm and most had either Alzheimer's disease or vascular dementia. All had mild (45%) to moderate dementia (55%) on the Clinical Dementia Rating scale;[15] could communicate, hear and see well enough to participate in the group; had no major physical illness or disability, or diagnosed intellectual disability

Woods et al *Cochrane* 2012; Orrell et al *BJPsychiatry* 2014; D'Amico et al, *submitted*



NICE-SCIE Guideline (2007, being updated 2014?) reviews evidence across the full range of treatment and care options.

Other treatments

Comorbid dementia & depression:

- Sertraline & mirtazapine equally effective, but …
- Mirtazapine more cost-effective because of effect on **carer time**

Comorbid dementia & anxiety:

- CBT is effective & cost-effective

People with dementia with fractured hip:

- Length of inpatient 43 vs 26 days

NCCMH *NICE-SCIE Guideline* 2012; Banerjee et al *Lancet* 2012; Romeo et al *Brit J Psychiatry* 2013; Spector et al *Brit J Psychiatry* 2014; Henderson et al PSSRU 2007

Home-based care

Surprisingly little evidence on what works in home care.

Patterns of home support provided to people with dementia and their carers - study led by David Challis (reporting 2015)

Reablement home care – no direct evidence for people with dementia, but Glendinning et al (2010) report some success.

Glendinning et al SPRU/PSSRU report 2010; Hirani et al *Age & Ageing* 2014; Henderson et al *Age & Ageing* 2014

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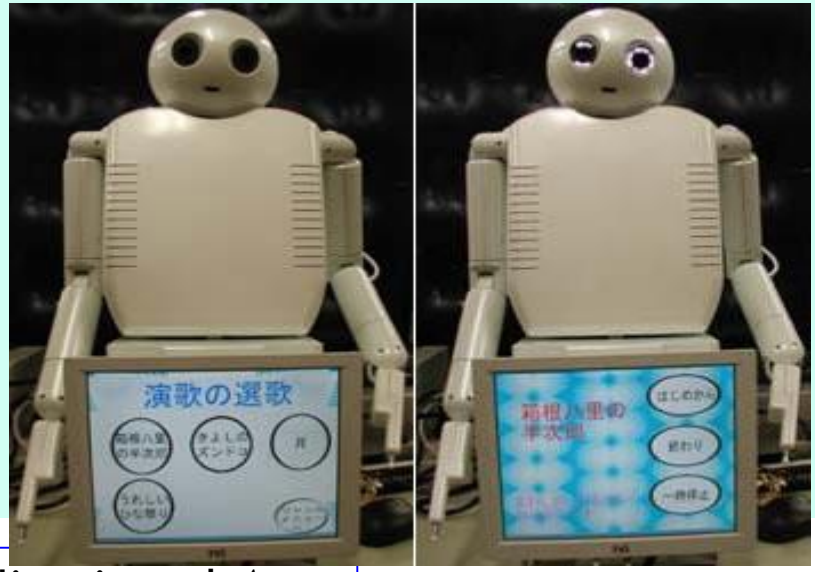
Telecare is widely seen as long-term solution. However, today's evidence is not encouraging:

- **WSD trial** → telecare for (all) older people offers 'small relative benefits' over usual care, but is not cost-effective (cost per QALY = £297,000).

So, are robots the future?



Glendinning et al SPRU/PSSRU report 2010; Hirani et al *Age & Ageing* 2014; Henderson et al *Age & Ageing* 2014

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Case management

Evidence on case management is also mixed.

*Cochrane Review (*Siobhan Reilly et al) due to be published soon.

Reilly et al *Cochrane Review*, forthcoming

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Attitudes and awareness

Policy aims in England:

- to build **dementia-friendly communities**
- to raise **public awareness**

Achievements:

- Rapid growth in numbers of individuals trained in **dementia awareness**; plus schools, shops, banks, transport orgs, …
- Have **attitudes** changed? Yes but only modest improvement
- Similar evidence from other countries (e.g. Germany)
- World Alzheimer Report 2012 – still **widespread stigma** and social exclusion of people with dementia

ADI *World Alzheimer Report 2012: Overcoming the Stigma of Dementia;* von dem Knesebeck et al *Int Psychogeriatrics* 2014

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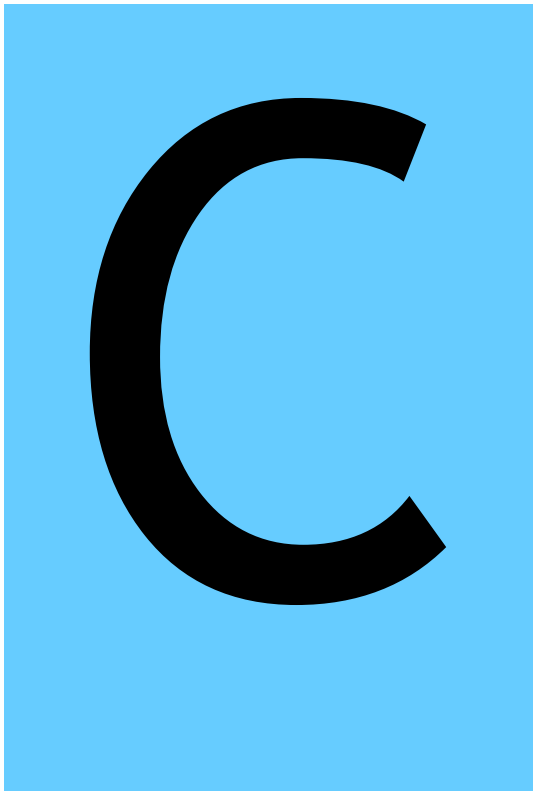

New scenarios?

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

A. ***Current care scenario***: Care and support as currently provided in England [*as illustrated earlier*]

B. ***No-diagnosis scenario***: Dementia is not diagnosed or treated.

C. ***Diagnosis-only scenario***: Dementia is diagnosed but not treated.

D. ***Improved care scenario***: Dementia is diagnosed, followed by evidence-based, 'improved' care and support.

E. ***Disease-modifying scenario***: Disease-modifying treatments are available to slow progression or delay.

Knapp et al. *Scenarios of Dementia Care* 2014

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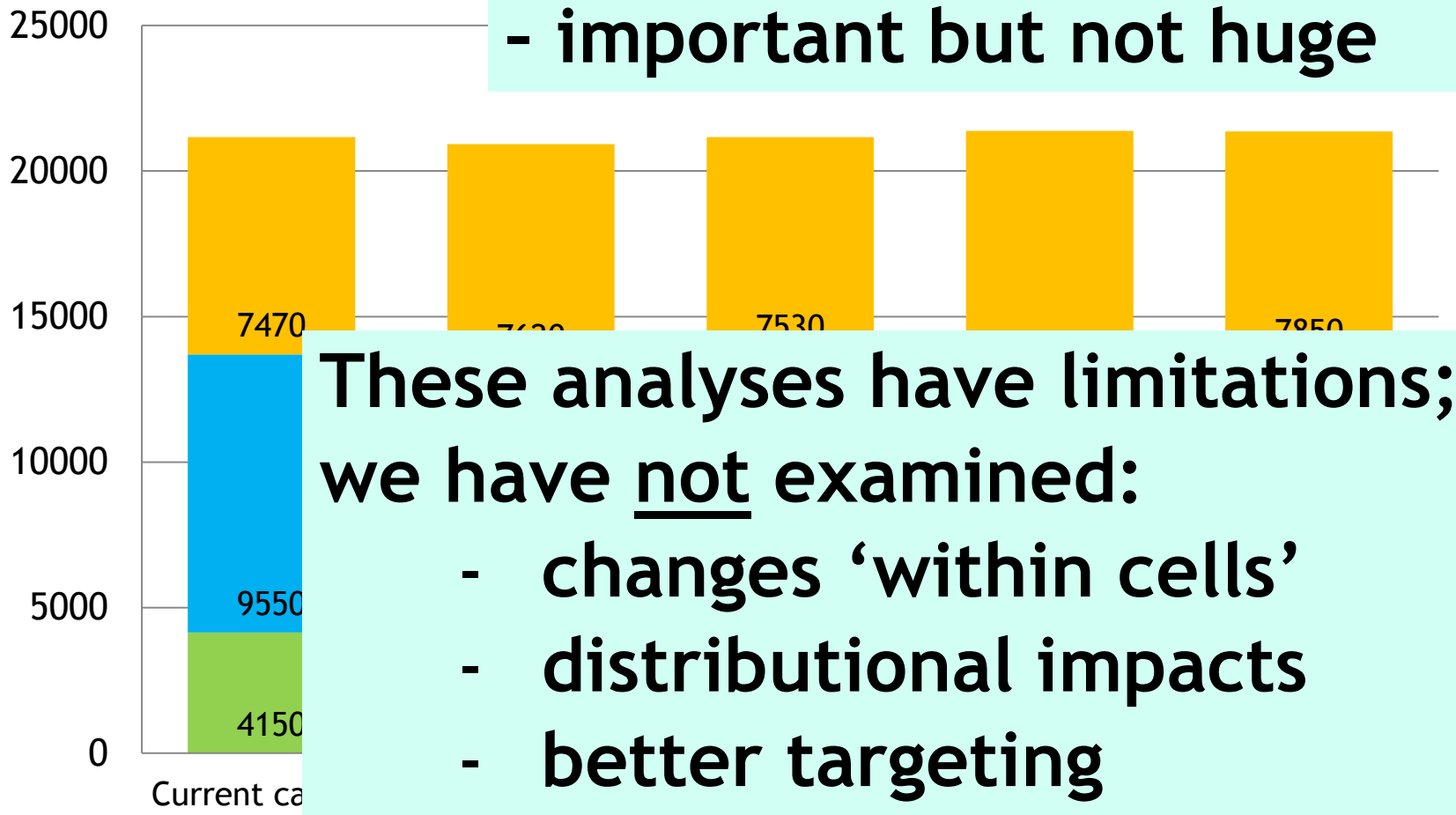
Improving dementia care: modest effects on costs (£ millions, 2012 prices, UK)



Quality of life improvements - important but not huge

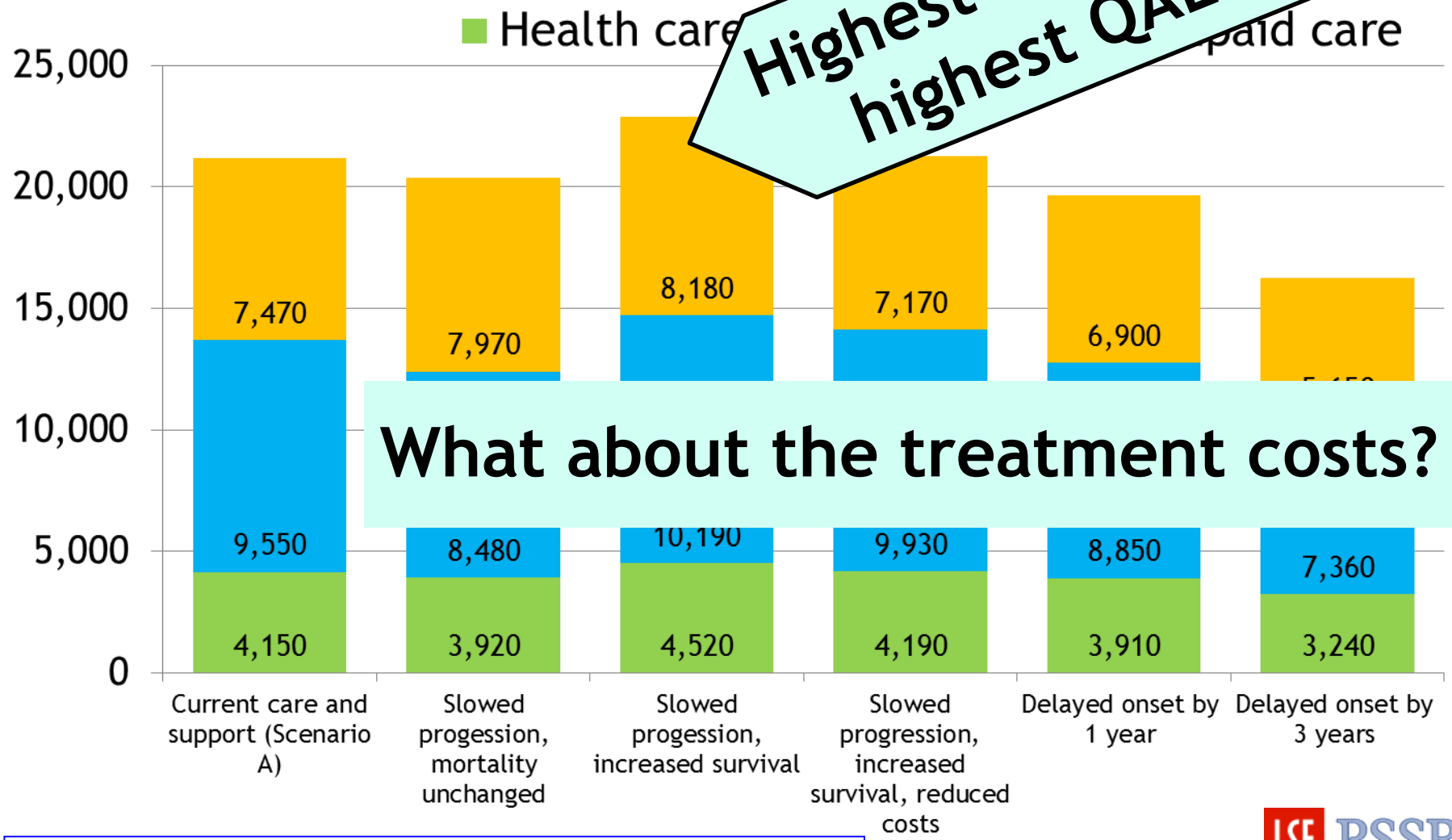
These analyses have limitations; we have not examined:

- changes 'within cells'
- distributional impacts
- better targeting
- stacking of impacts

Knapp et al. *Scenar*

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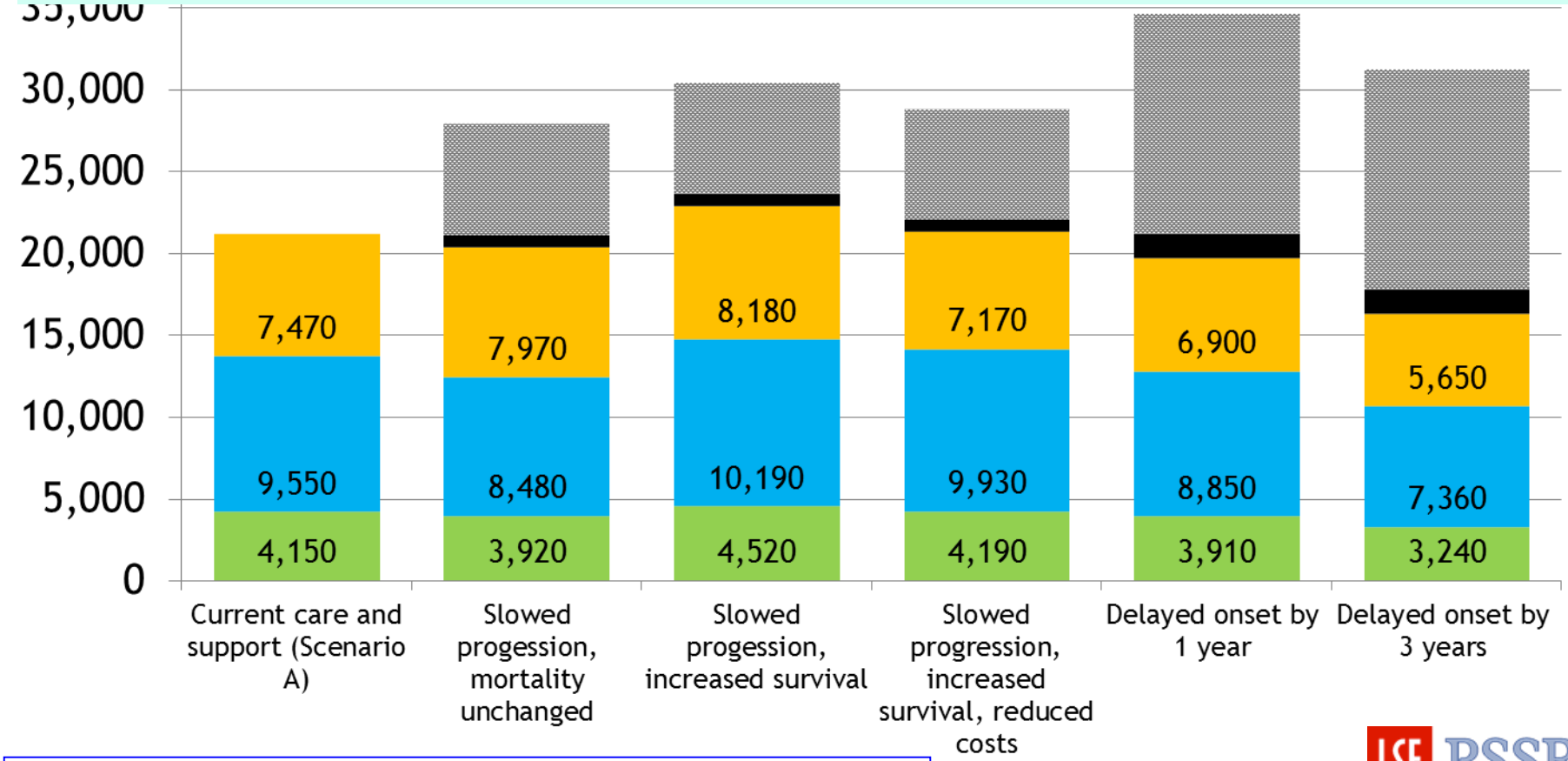
Treatment costs will have a huge influence, depending on price and number treated

These treatment costs are purely hypothetical



Knapp et al. *Scenarios of Dementia Care* 2014

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D New directions?

World Dementia Council: priorities (1)

- **Finance** – propose new incentives and financial structures that drive new investment by lowering risk and increasing reward.
- **Research collaboration** – develop incentives for new research partnerships between government, academia and industry, with an emphasis on entrepreneurial effort and a patient-focused research approach.
- **Regulation and trials** – seek to harmonise the regulatory pathway and find other ways to make it more flexible and efficient, in order to accelerate drug development.

World Dementia Council: priorities (2)

- **Sharing knowledge** – support global efforts to build inventories of research activity & databases. Address disincentives for collaboration in both industry and academia. Encourage data-sharing. Establish networks for synthesising and disseminating knowledge.
- **Health and care** – identify and disseminate innovative practice in dementia care. Make these and existing practices available to people with dementia, families & carers globally.
- **Awareness** – raise public awareness re. economic and social challenges and the urgent need for a radical global response. Change policies and practice to increase diagnosis rates and improve treatment and care.

So … the future should be two-pronged

- Dementia has become a **major, world-wide focus** for long-term care and health care.
- … with many associated **challenges**
- But new and encouraging evidence is emerging of **effective and cost-effective** care and treatment.
- However, doubts about long-term **affordability** of currently known interventions.
- And so the search for **new, better care and treatment interventions** must continue apace.
- The future needs to be two-pronged: **cure and care.**

Thank you

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