THE LONDON SCHOOL OF ECONOMICS AND POLITICAL SCIENCE

PSSRU

Personal Social Services Research Unit

Buckfast Abbey

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The Dementia Challenge

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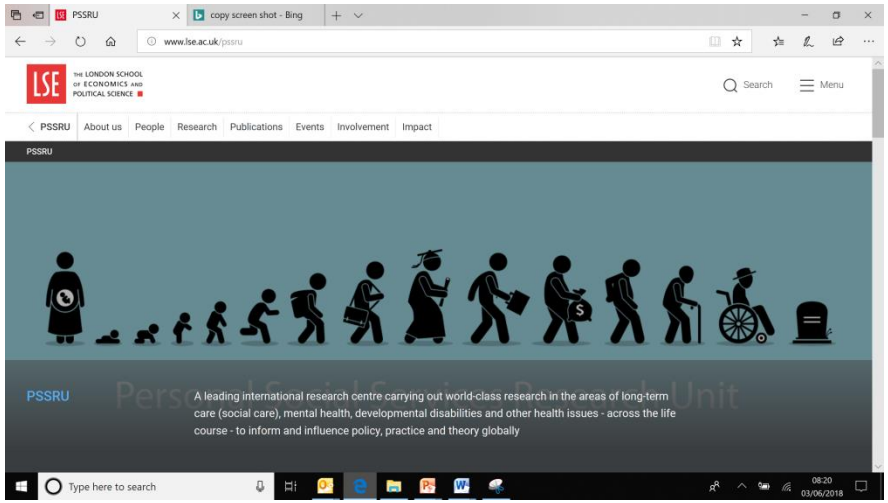
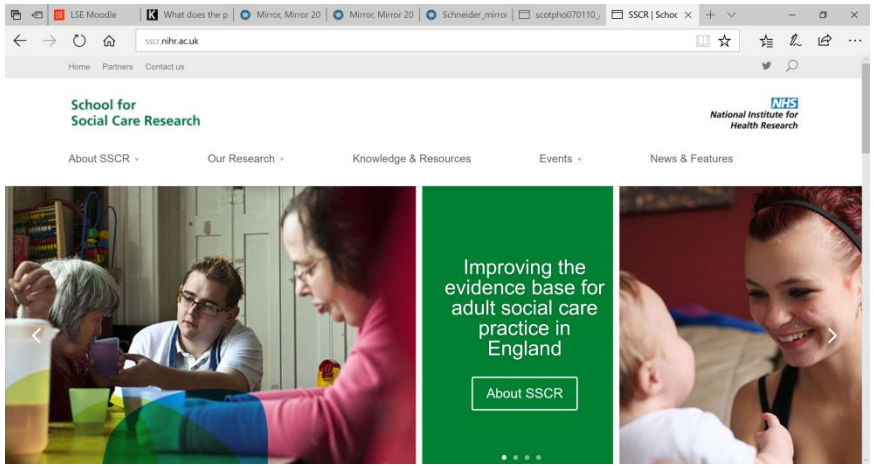
& NIHR School for Social Care Research

PSSRU (… soon CPEC) @ LSE *and* NIHR School for Social Care Research





Themes

- Research on health & social care …
- … primarily to inform policy discussion and/or service development

Topics

- Social care (long-term care)
- Mental health (children, adults)
- Dementia
- Autism

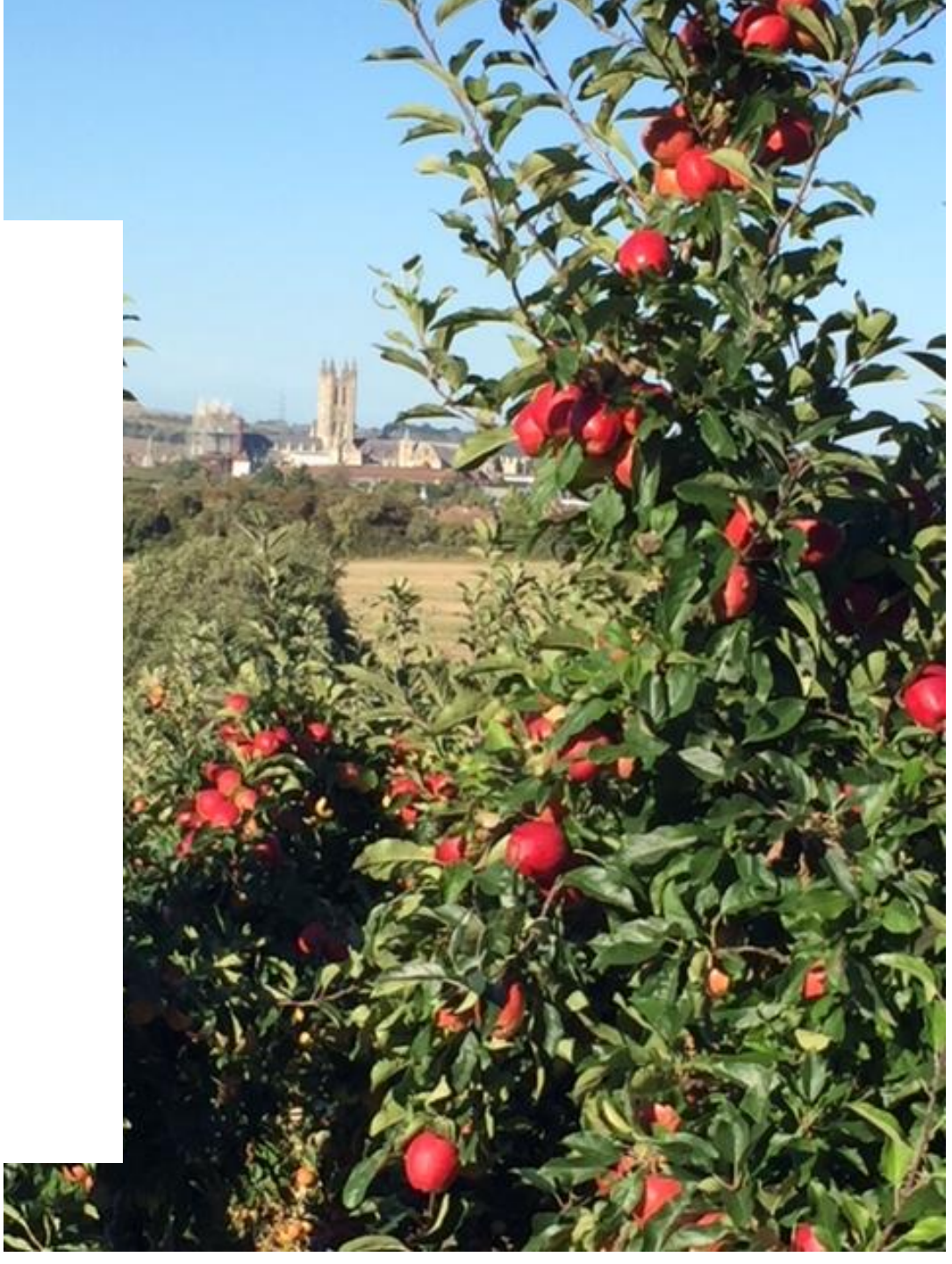
Structure

A. Dementia: the nature of the challenge

C. MODEM

D. STRiDE

E. Discussion



A

Dementia - the nature of the challenge

Dementia: collection of brain disorders

- Collection of different brain disorders that trigger loss of brain function – not reversible, usually progressive, eventually severe.
- Most common is Alzheimer's disease (62% of people with diagnosed dementia)
- Other types include: vascular dementia (17%), mixed dementia (10%), frontotemporal, Lewy body, Parkinson's type
- Symptoms - memory loss, confusion, problems with speech and understanding.

Prevalence

Estimates based on **MODEM** modelling (see later)

650,000 older people with dementia in England in 2015:

- approximately 250,000 in ***care homes***
- 250,000 receive ***unpaid care***
- 100,000 receive ***community care***

Prevalence rate of 6.7% in people aged 65+ (analysis of CFAS II data); with steep age gradient (doubles every 5-year age group):

1.6% (M) 1.0% (F) ages 65-69,

2.9% (M) 3.1% (F) ages 70-74 …

… 22.1% (M) 30.8% (F) ages 90+

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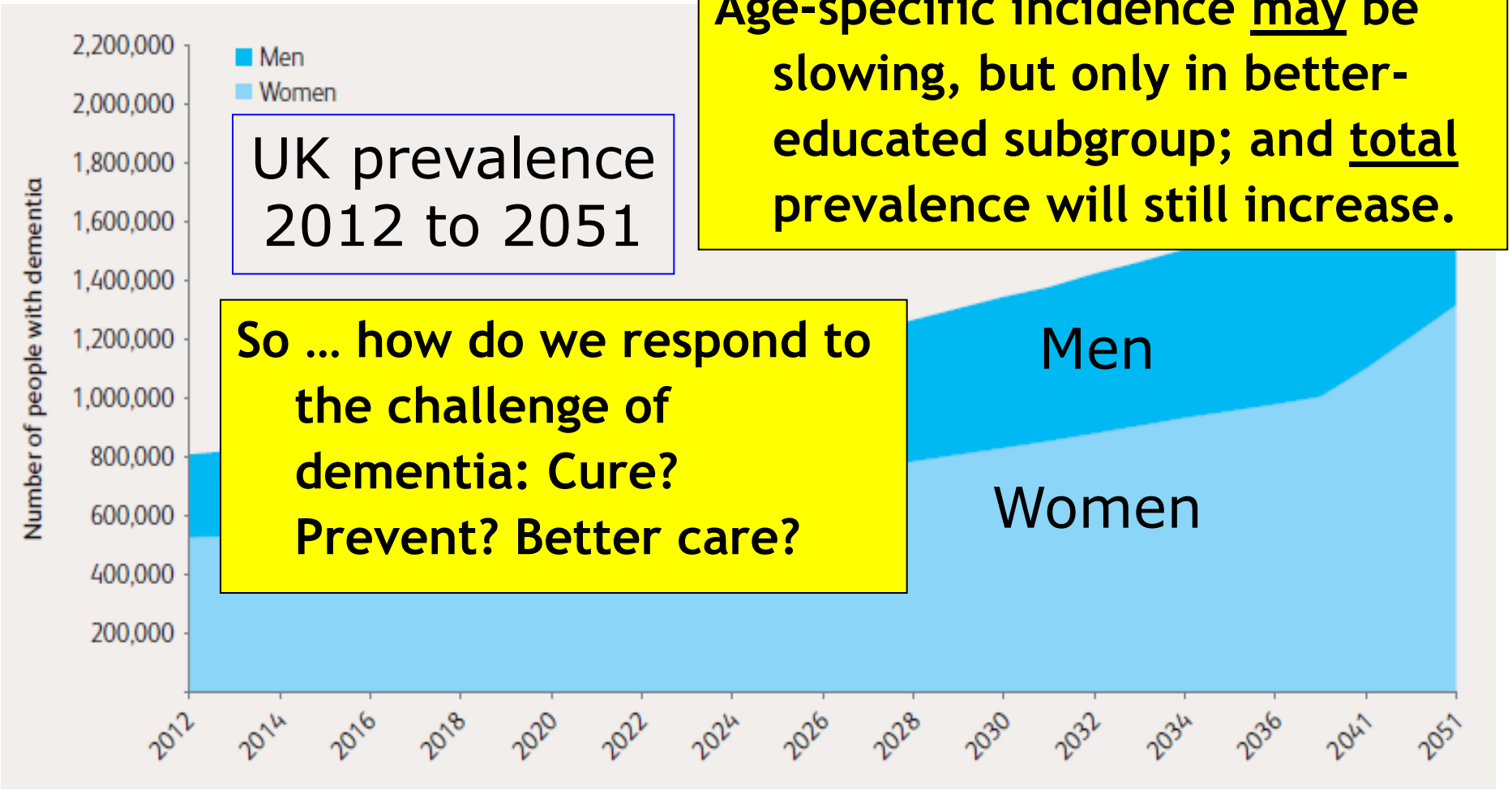
Impacts of dementia

- Reactions to diagnosis
- Communicating
- Losing independence
- Emotions and feelings
- Self-confidence
- Sense of identity
- Changes in behaviour
- Relationships, roles and responsibilities
- Carer health, particularly mental health
- … also … paying for care

Projected prevalence of dementia (UK)

850,000 people with dementia in the UK today



Prince et al *Dementia UK; 2nd Edition* 2014; Matthews et al, *Lancet* 2013

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Cure?

No disease-modifying treatments yet

99.6% failure rate of medication trials for Alzheimer's disease, 2002-2012 (Cummings et al. *Alz Res Ther* 2014)

Why?

- Inherent inaccessibility & complexity of the brain
- Symptoms may emerge 10+ years after disease starts
- Not enough research / researchers?
- Insufficient protection for IP?

Factoring in difficulties & costs of diagnostic tests - will a 'cure' be affordable, even in HICs?

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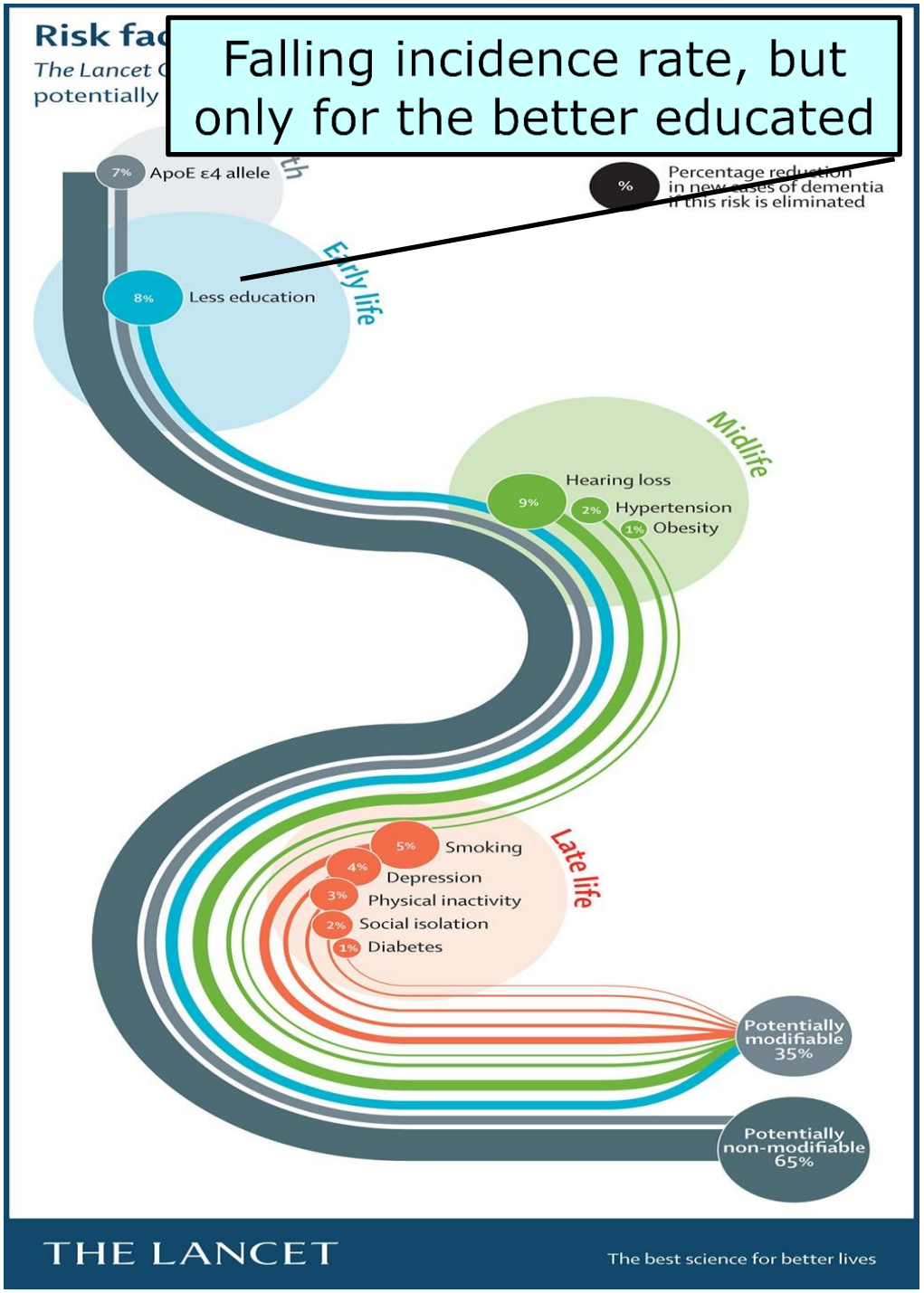
Prevent?

Known risk factors:

- Genes (*at birth*)
- Education (*early life* +)
- Hearing loss, hypertension, obesity (*mid-life*)
- Smoking, depression, physical inactivity, social isolation, diabetes (*late-life*)

Overall population-attributable risk = 35%

Livingston et al *Lancet* 2017



Care?

- ***Medications*** – symptomatic, Alzheimer's disease
- ***Psychosocial therapies***: e.g. cognitive stimulation, cognitive rehabilitation
- ***Care arrangements***: e.g. home care, telecare, case management, nursing homes
- ***Carer support***: e.g. training, awareness, relaxation, psychosocial therapies
- ***End-of-life care***

… recognising also that people with dementia have (on average) 3 co-morbid conditions

… so treatment of those conditions may also be complicated by the individual's dementia.

NICE dementia guidelines 2018: summary

- Involving people living with dementia
- Providing information
- Advance care planning
- Diagnosis
- Review after diagnosis
- Care coordination
- Making services accessible
- Interventions to promote cognition, independence and wellbeing – what to offer and not offer
- Medications for AD and non-AD at different disease stages
- Managing non-cognitive symptoms (e.g. agitation, aggression, distress, psychosis)
- Treating comorbidities
- Carer support

B

The MODEM project

MODEM: core research questions

ESRC/NIHR-funded, collaborative project; PI Martin Knapp (PSSRU, LSE)

Core questions:

1. How many people with dementia will there be in England over the period to 2040?
2. What will be the costs of their treatment, care & support **under present arrangements**?
3. How could future costs and outcomes change (in level and distribution) **if evidence-based interventions were more widely implemented**?

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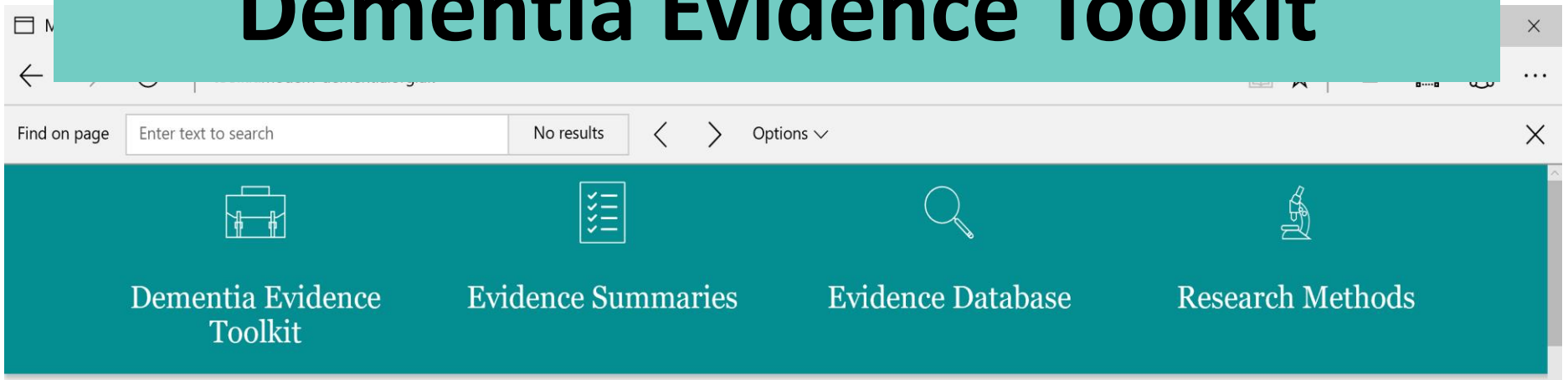
Dementia Evidence Toolkit



The MODEM Toolkit includes evidence summaries

Also → currently undertaking a **systematic review of cost-effectiveness evidence** in relation to interventions for people living with dementia & carers

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Population Ageing & Care Simulation (PACSim model)

PACSim is a dynamic microsimulation model which

- Simulates future health conditions, dependency and survival of a set of real individuals (base population) aged 35 years and over
- Feeds results into the PSSRU macro-simulation model to estimate unpaid and formal care and associated expenditure
- Enables evaluation of the effect of interventions (lifestyle, dementia) on future dependency

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Complexity of morbidity

Age and Ageing 2018; **0:** 1–7
doi: 10.1093/ageing/afx201

Projections of multi-morbidity in the older population in England to 2035: estimates from the Population Ageing and Care Simulation (PACSim) model

Andrew Kingston[1], Louise Robinson[1], Heather Booth[2], Martin Knapp[3], Carol Jagger[1], for the MODEM project

MODEM study on dementia projections & scaling up of evidence-based interventions (finishes soon)

- From 2015 to 2035, numbers of older people with **4+ diseases will double**; a third will have mental ill-health (particularly dementia or depression)
- Two-thirds(+) of gain in years of life at age 65 will be years with **4+ long-term conditions (complex multi-morbidity)**
- Gain in years spent with multi-morbidity (2+ diseases) will exceed gains in life expectancy → **expansion of morbidity**

[Data from CFAS II, ELSA, Understanding Society]

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PACSim: Years needing care, 2015 to 2035

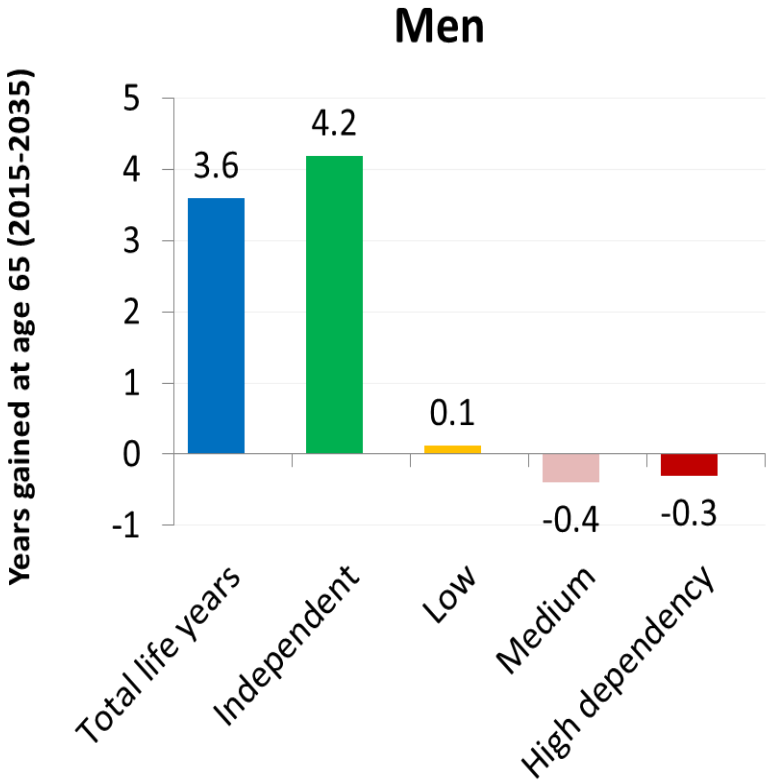
Forecasting the care needs of the older population in England over the next 20 years: estimates from the Population Ageing and Care Simulation (PACSim) modelling study

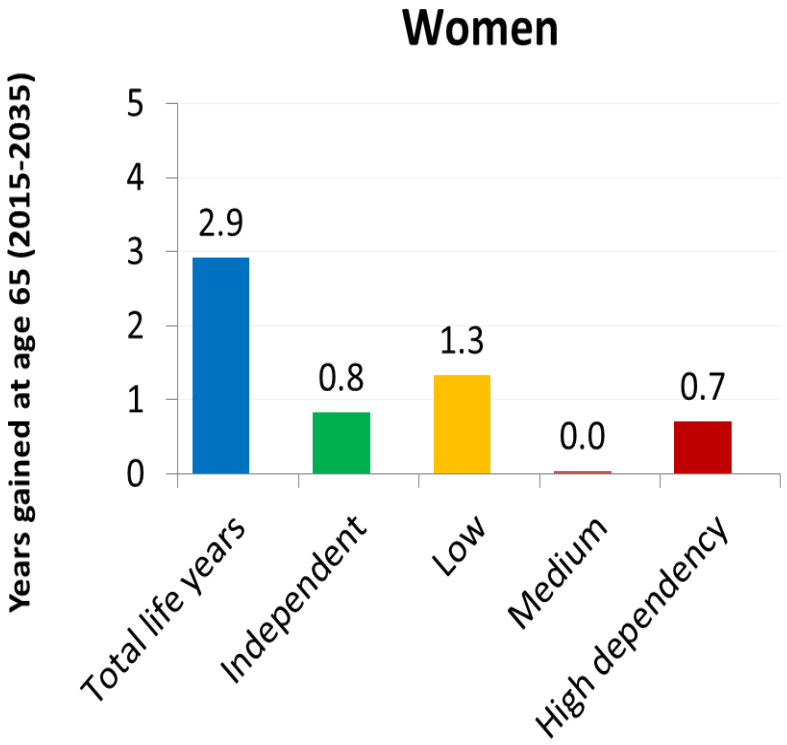
Andrew Kingston, Adelina Comas-Herrera, Carol Jagger for the MODEM project*

Summary

Background Existing models for forecasting future care needs are limited in the risk factors included and in the assumptions made about incoming cohorts. We estimated the numbers of people aged 65 years or older in England and the years lived in older age requiring care at different intensities between 2015 and 2035 from the Population Ageing and Care Simulation (PACSim) model.

Lancet Public Health 2018; 3: e447–55
Published Online August 30, 2018
http://dx.doi.org/10.1016/S2468-2667(18)30118-X





Kingston A, Comas A, Jagger C. *Lancet Public Health* 2018; 47: 374–380

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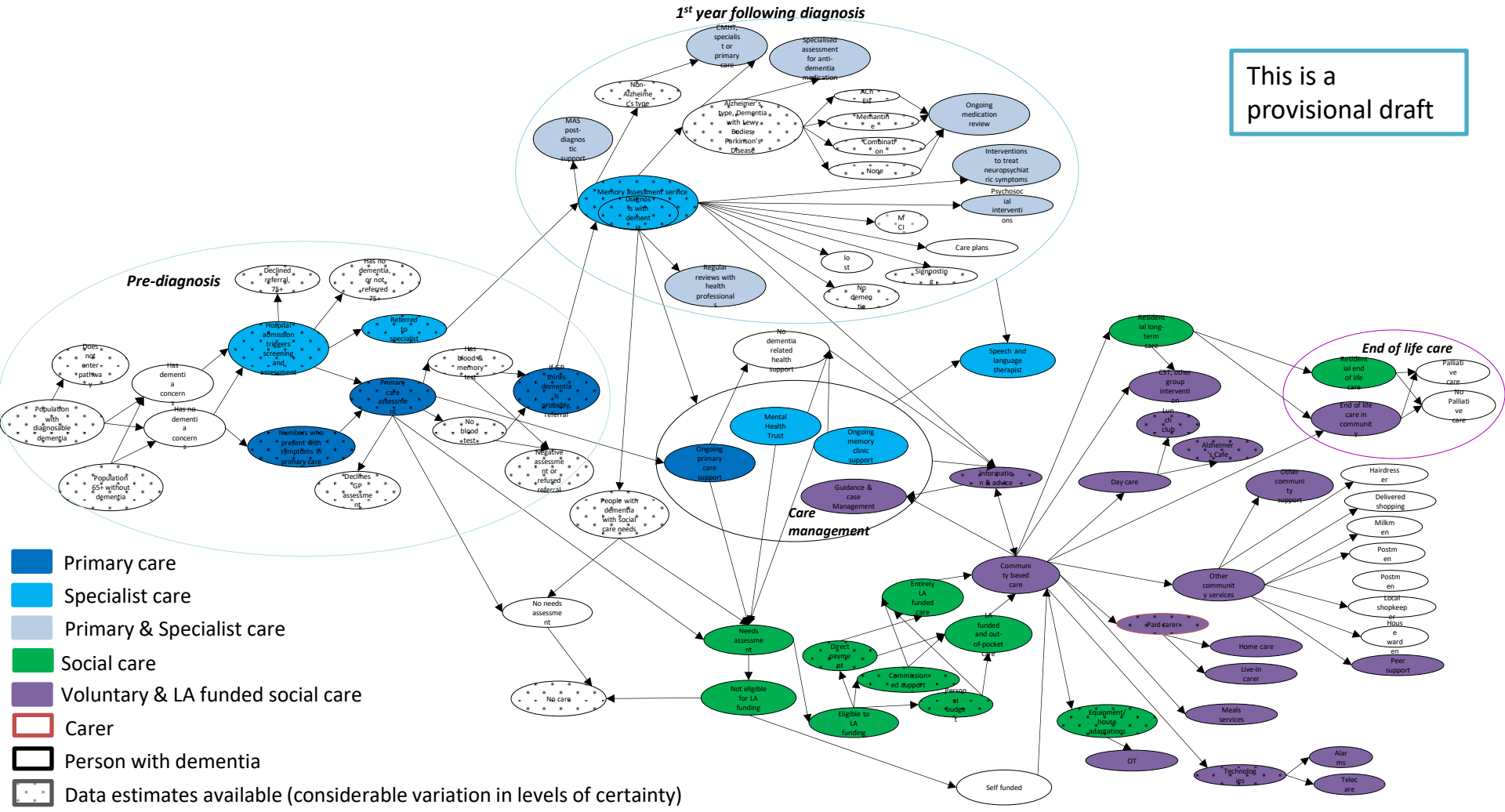
Care pathways: people with dementia in England



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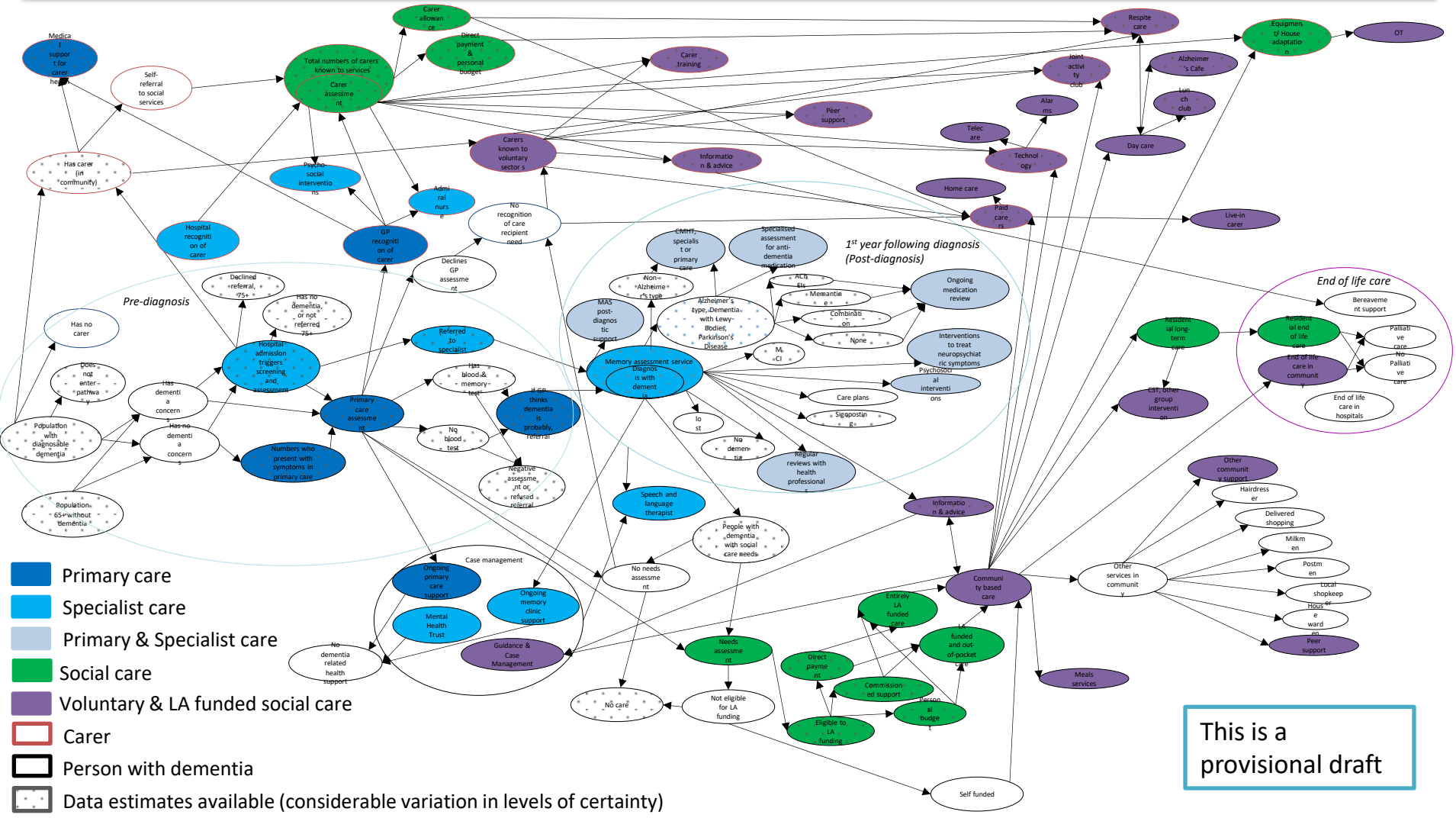
Care pathways: people with dementia & carers



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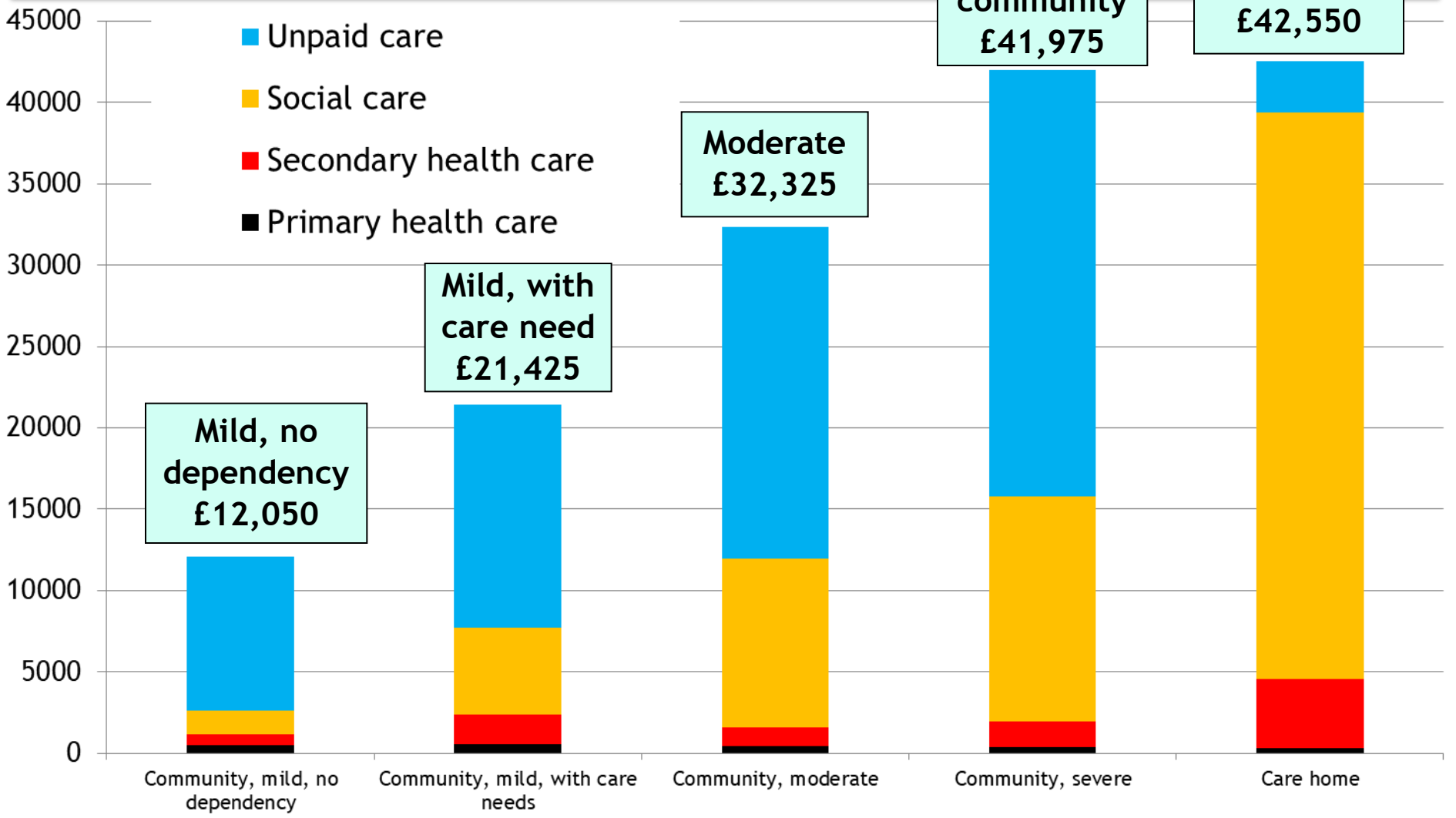
Average annual cost per person - by dementia severity & ca[illegible]



Estimates from the MODEM study; unpublished 2018

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Projected costs: data & assumptions

- Office for National Statistics 2014-based principal ***population projections***
- PACSim findings on trends in ***cognitive impairment & dependency*** by age, gender, education
- Detailed patterns of ***formal care & unpaid care*** from local intensive cohort and other sources (incl. ELSA)
- Unchanged pattern of care in terms of ***balance between unpaid, community-based and residential care***
- ***Unit costs*** of care rise in real terms in line with OBR assumptions on productivity and earnings (plus National Living Wage effect to 2020)

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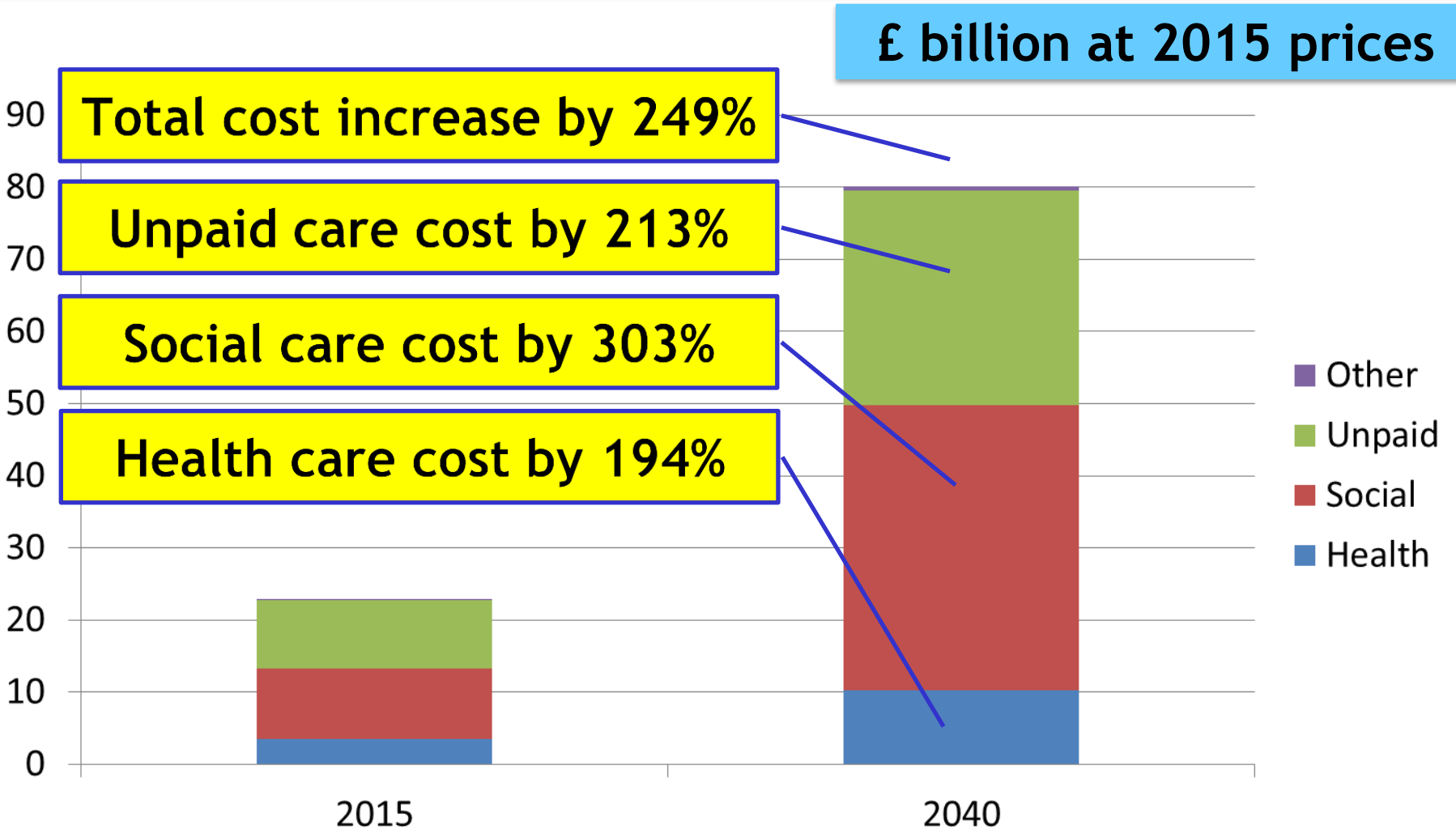
Projected costs of dementia care



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What would happen if we scaled up effective interventions?

From *MODEM Dementia Evidence Toolkit* & systematic review of cost-effectiveness evidence:

- Cognitive stimulation therapy (CST)*
- Carer support (START)
- Anti-dementia medications (monotherapy & combination therapy at different severity levels)*
- Person-centred care intervention in care homes (WHELD)*

*not shown today

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START: what is it?

STrAtegies for RelaTives (START): Individual programme of 8 sessions over 8-14 weeks. Delivered by psychology graduates + manual. Carers given techniques to:

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

English adaptation of *Coping with Caregiving Programme* in USA

Livingston et al *BMJ* 2013

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START: effectiveness & cost-effectiveness

Pragmatic RCT: START vs usual support; n=260 family carers; North London. Carers interviewed 4, 8, 24 & 72m after intervention ended. Economics too.

Carer health & quality of life

- Mental health gains at 8m & 24m
- QALY gains at 8m & 24m

Person with dementia health & quality of life

- No differences in health or QOL

Costs (not significant)

- Increased carer healthcare costs at 8m
- Reduced total health & social care service costs at 24m

Cost-effectiveness

- £118 per 1-point change on HADS-total; £6000 per QALY at 8m
- START *dominates* usual care at 24m: better outcomes, lower costs

Livingston et al *BMJ* 2013

Knapp et al *BMJ* 2013

Livingston et al *Lancet Psych* 2014

Livingston et al *Brit J Psychiatry* 2019 (soon)

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START: scaling-up, 2015 to 2040

Carers with better mental health & QOL

- 43,000 in 2020
- 63,000 in 2040

Additional **QALYs**

- 1300 in 2020
- 1900 in 2040

No estimates for **unpaid care costs**

Health & social care service savings

- £50m in 2020
- £105m in 2040

Over 24m:

- better outcomes
- lower costs

By 72m: Still effective and cost-effective

TENTATIVE RESULTS

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The STRiDE project

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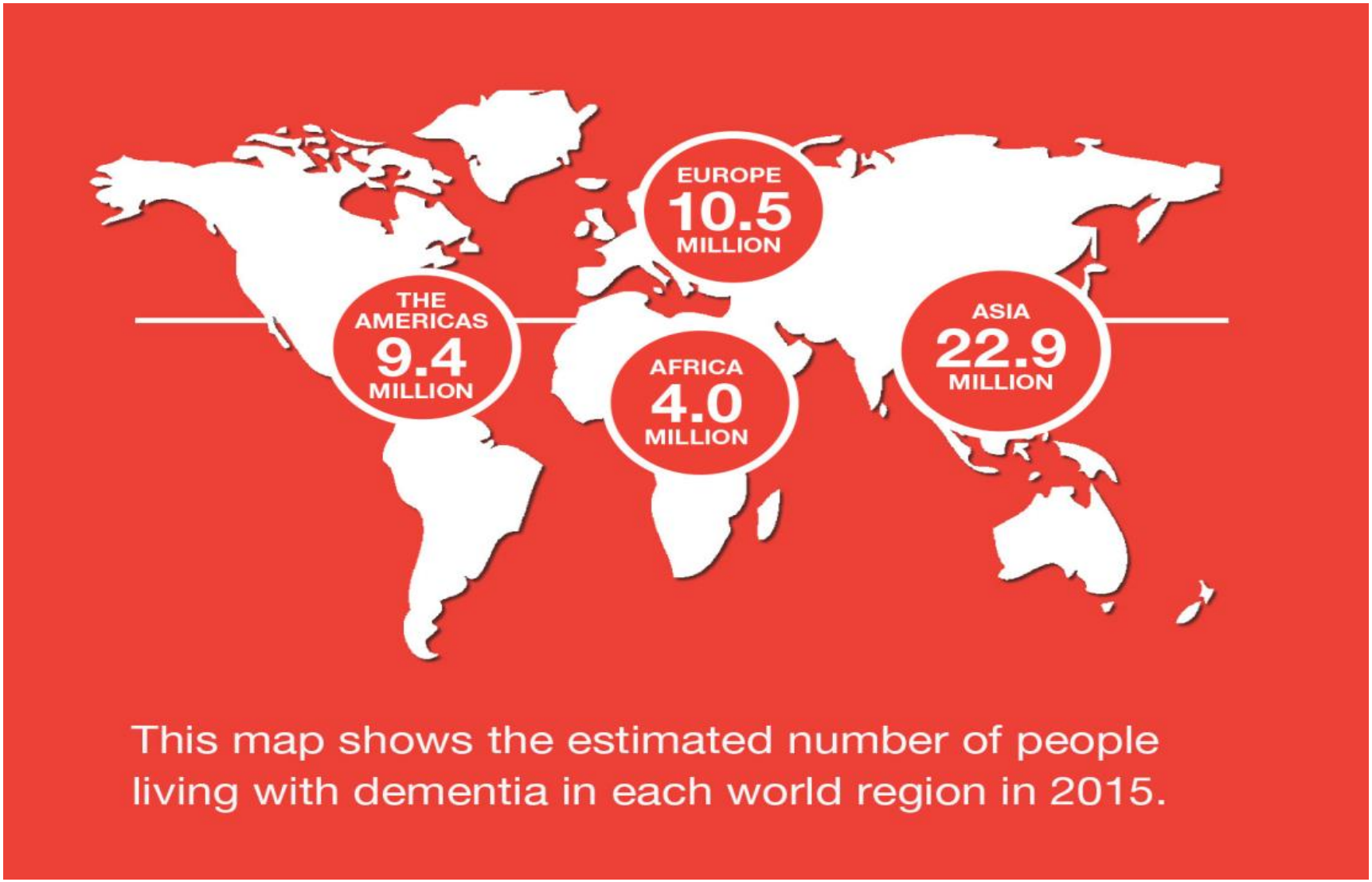
Global prevalence of dementia 2015



www.alz.co.uk/worldreport2015

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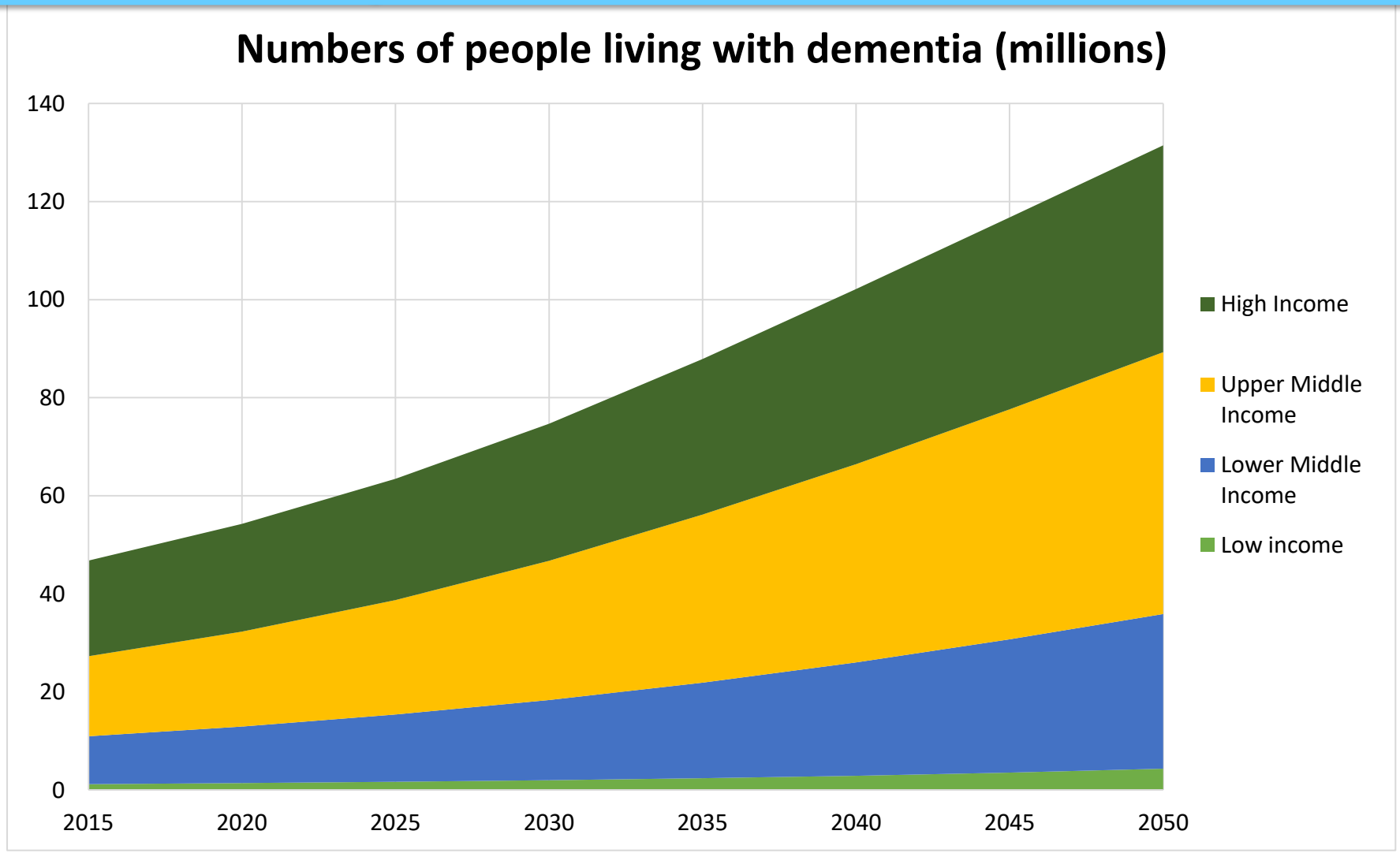
Projected global growth in dementia prevalence to 2050



www.alz.co.uk/worldreport2015

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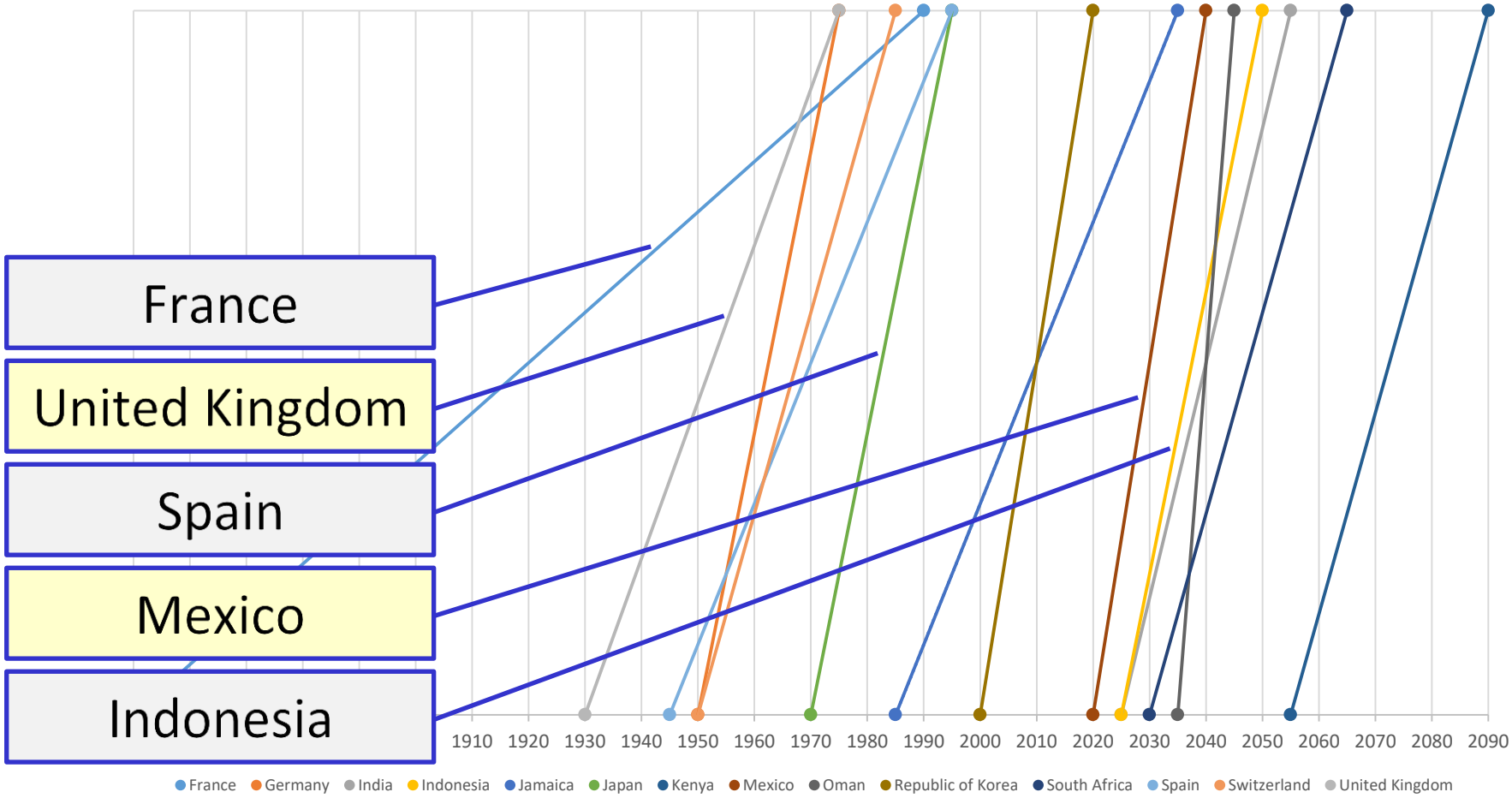
Projected population ageing

Time expected for the population aged 65+ to increase from 7% to 14%



WHO Global Health and Aging 2011, from Kinsella & He (2008), US Census Bureau (2009)

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STRiDE: Strengthening responses to dementia in developing countries

Primary objective: To help improve dementia care systems so that:

1. people living with dementia can **live well**
2. family & other carers do not carry **excessive costs**, risk impoverishment or compromise their own health

Secondary objectives: To work with local partners in 7 countries to:

- build ***capacity in generating/using research evidence*** to support policies for improvement of dementia care, treatment & support
- build up research evidence on ***what works in dementia*** in LMICs
- better understand ***impacts of dementia in various cultural, social, economic contexts*** to help countries develop responses
- help develop, finance, plan, implement & evaluate ***national dementia plans***.

STRiDE

Funded by UKRI (ESRC), £7.8 million, Oct 2017 – Dec 2021

UK Research and Innovation

GCRF Global Challenges Research Fund

- Large project: 10 work packages, 7 countries
- Duration: October 2017 (project management; full start January 2018) to December 2021
- Collaboration between researchers and NGOs to provide tools for policy change on dementia

UK Research and Innovation GCRF Global Challenges Research Fund

www.stride-dementia.org / @STRiDEDementia

Why STRiDE? The challenges in low- and middle-income countries

- Lack of awareness and stigma → risk of abuse and neglect
- Unprepared health systems, lack of professional knowledge → missed opportunities for risk reduction, diagnostic & treatment
- Underdeveloped care systems → families (mostly women) bear full costs of dementia, emerging unregulated private sector
- "Competition" from other health challenges → Health and other care needs of older people are typically low on the political agenda
- Increasing evidence that unsupported family care is unsustainable, putting many at risk of impoverishment & neglect

STRiDE

UK Research and Innovation GCRF Global Challenges Research Fund

D

Discussion

Funding, disclaimer, conflict of interest

MODEM is funded by ESRC (now part of UKRI) and NIHR (part of the Department of Health and Social Care)

STRiDE is funded by UK Research & Innovation

START evaluation was funded by NIHR

Views expressed in this presentation are those of the presenter, and are not necessarily those of any of the research funders.

I have no conflicts of interest to declare.

Thank you

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