Launch event:

Comprehensive approach to modelling outcome and cost impacts of interventions for dementia (MODEM) project

Thursday 15 May 2014

LSE THE LONDON SCHOOL OF ECONOMICS AND POLITICAL SCIENCE

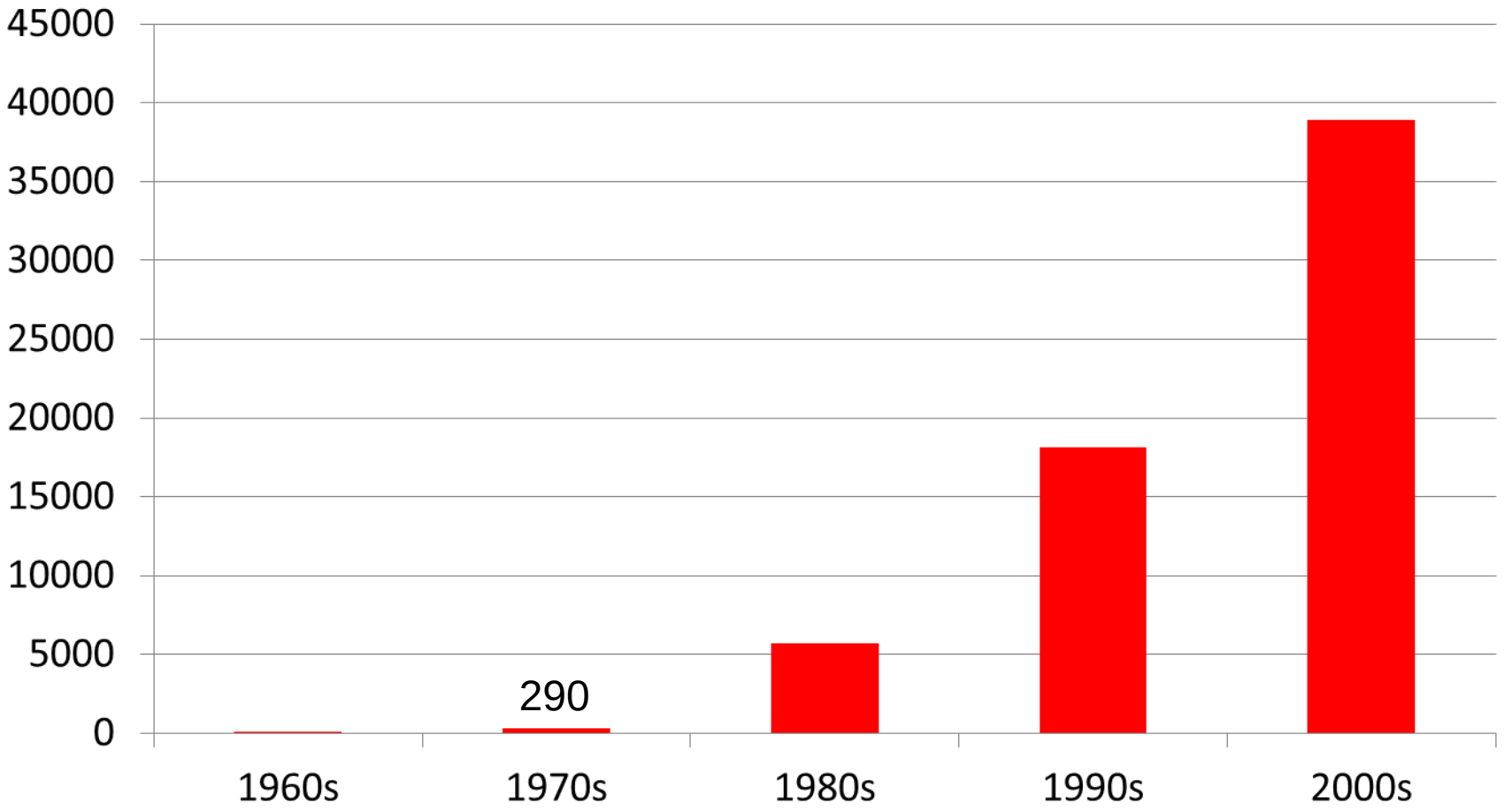
@PSSRU_LSE #MODEMlaunch

Email: Pssru.Modem@lse.ac.uk

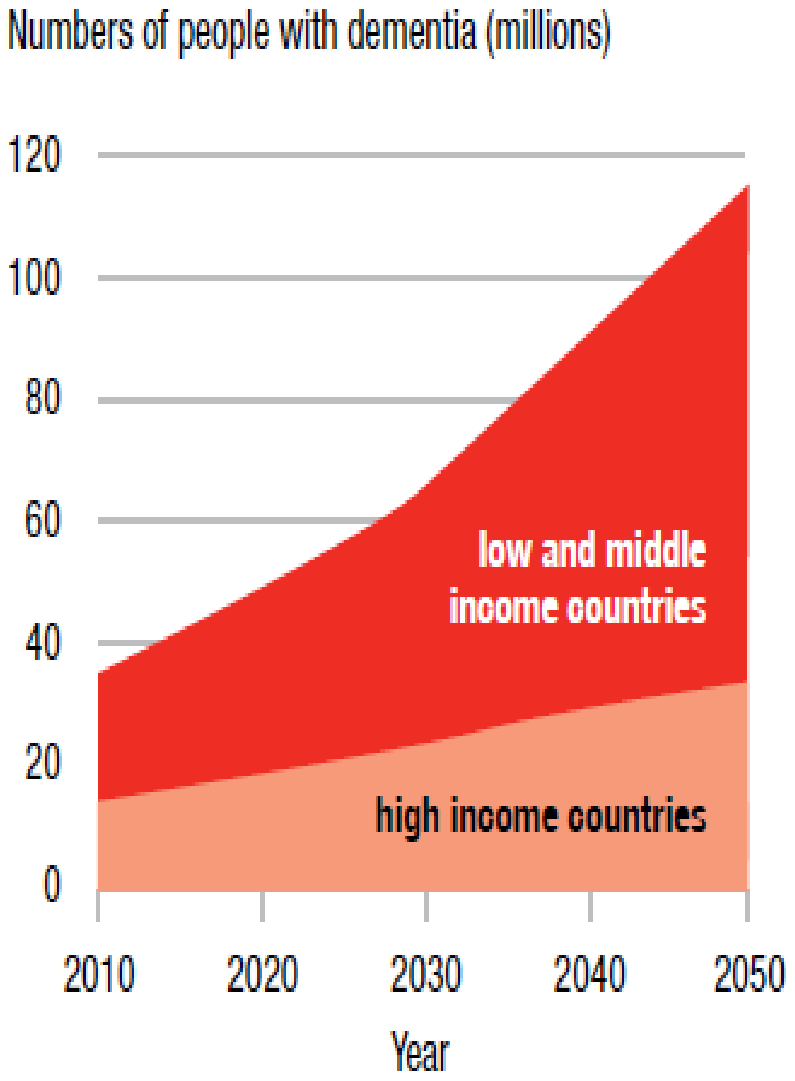
Reasons to be cheerful part 1

WE KNOW MUCH MORE ABOUT DEMENTIA

Numbers of papers on Alzheimer's Disease by decade

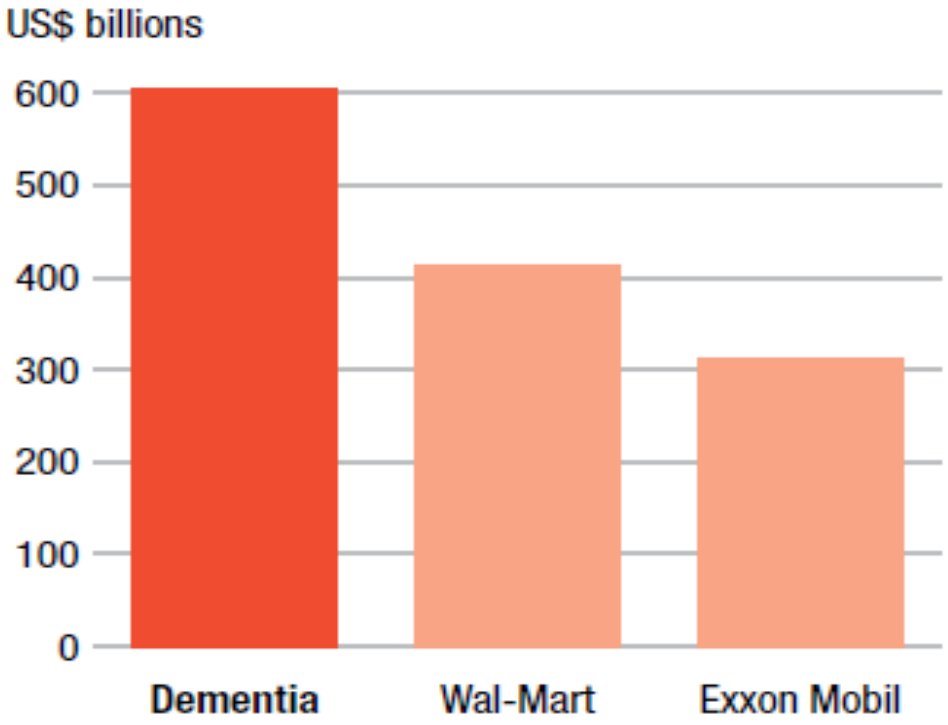


Growth of numbers of people with dementia



- **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



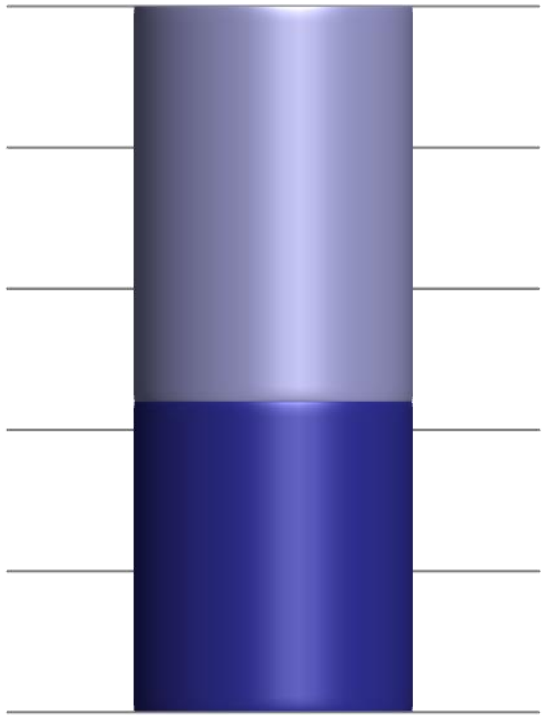
- The societal cost of dementia is already enormous.
- Dementia is already significantly affecting every health and social care system in the world.
- The economic impact on families is insufficiently appreciated.
- The total estimated worldwide costs of dementia are US$604 billion in 2010.
- These costs are around 1% of the world's GDP
  - **0.24% in low income**
  - **1.24% in high income**

Reasons to be cheerful part 2

BETTER DIAGNOSIS OF DEMENTIA

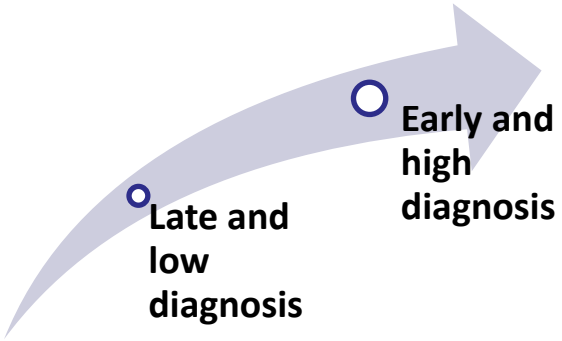
The fundamental problem - now

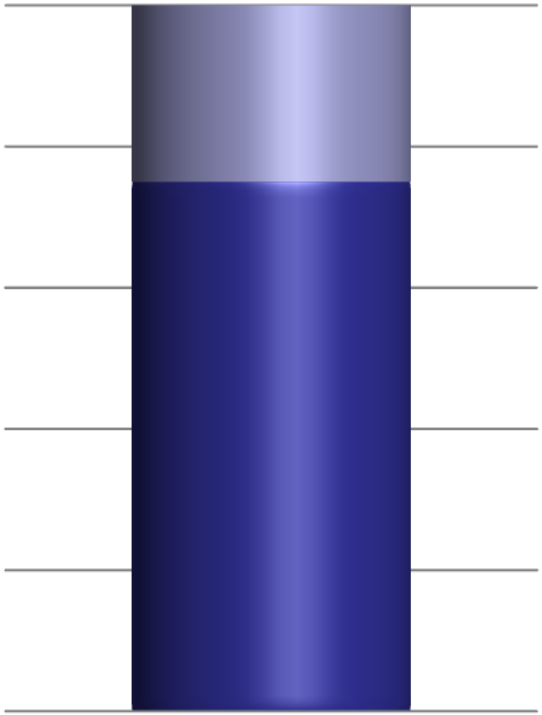
- **Only around 44% of people with dementia receive any specialist health care assessment or diagnosis**
- **When they do, it is:**
  - **Late in the illness**
  - **Too late to enable choice**
  - **At a time of crisis**
  - **Too late to prevent harm and crises**



The goal

- **70-80% of people with dementia receive accurate assessment and 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**

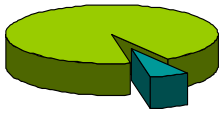




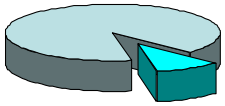
Services for early diagnosis and intervention in dementia for all – markers of quality

- **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
  - Communicate diagnosis well
  - Provide immediate support and care immediately from diagnosis

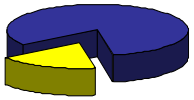
95% acceptance rate



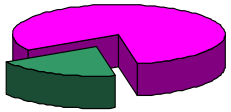
94% appropriate referrals



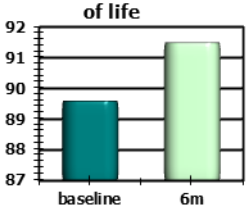
18% minority ethnic groups



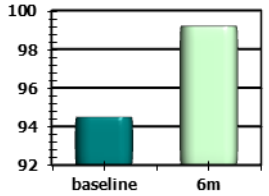
19% under 65 years of age



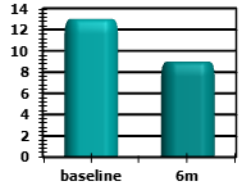
Improvement in self-rated quality of life



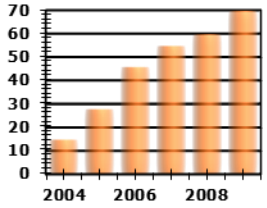
Improvement in carer-rated quality of life



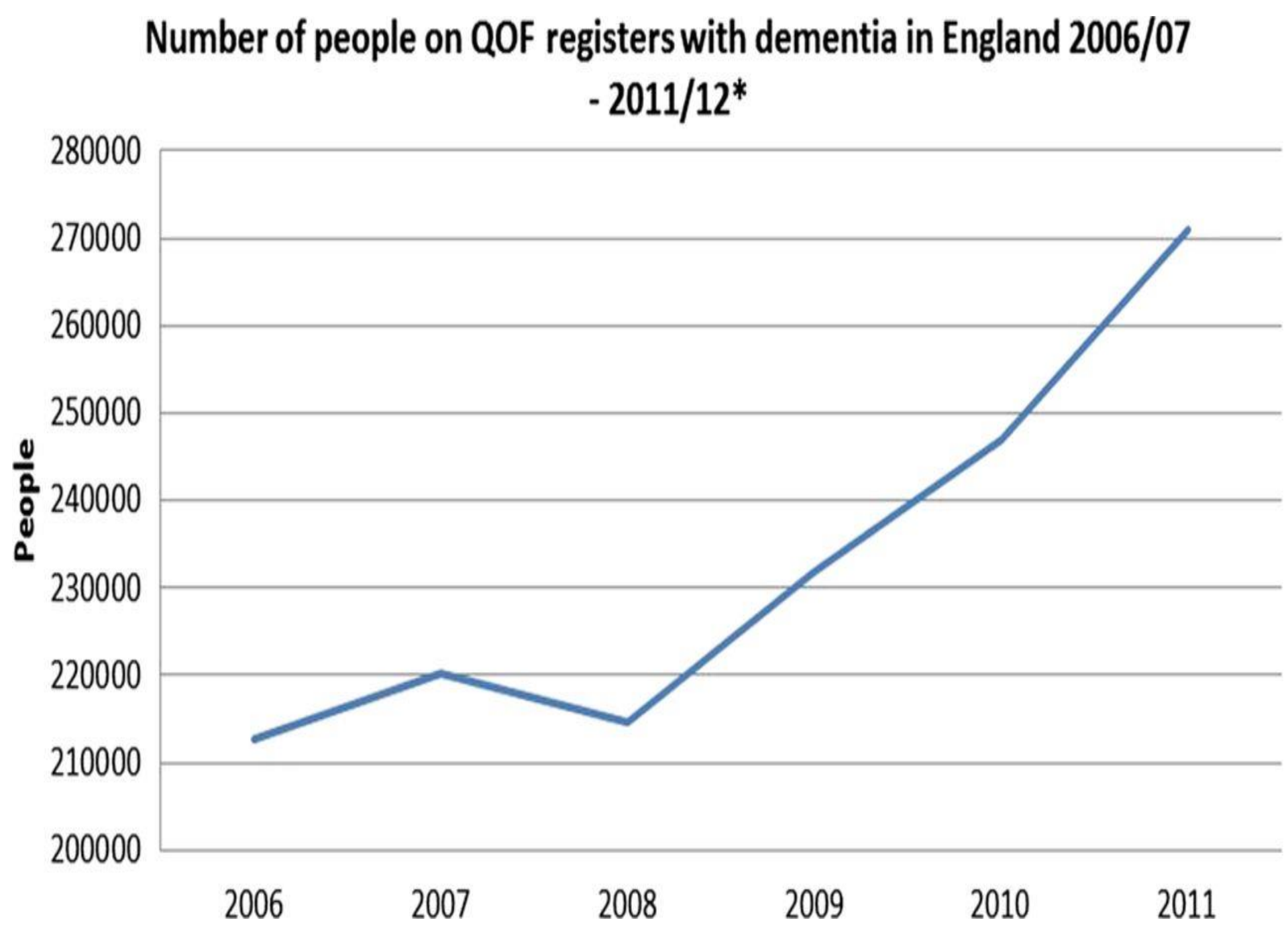
Decrease in behavioral disorder



Proportion of new cases diagnosed



Banerjee et al 2007, IJGP



Mukadam N et al. BMJ Open 2014;4:e004119

Reasons to be cheerful part 3

BETTER PREVENTION AND TREATMENT OF DEMENTIA

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A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II

Fiona E Matthews PhD [a], Prof Antony Arthur PhD [b], Linda E Barnes RGN [c], Prof John Bond BA [d], Prof Carol Jagger PhD [d], Prof Louise Robinson MD [d], Dr Prof Carol Brayne MD [c], on behalf of the Medical Research Council Cognitive Function and Ageing Collaboration

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Articles A two-decade comparison of prevalence of

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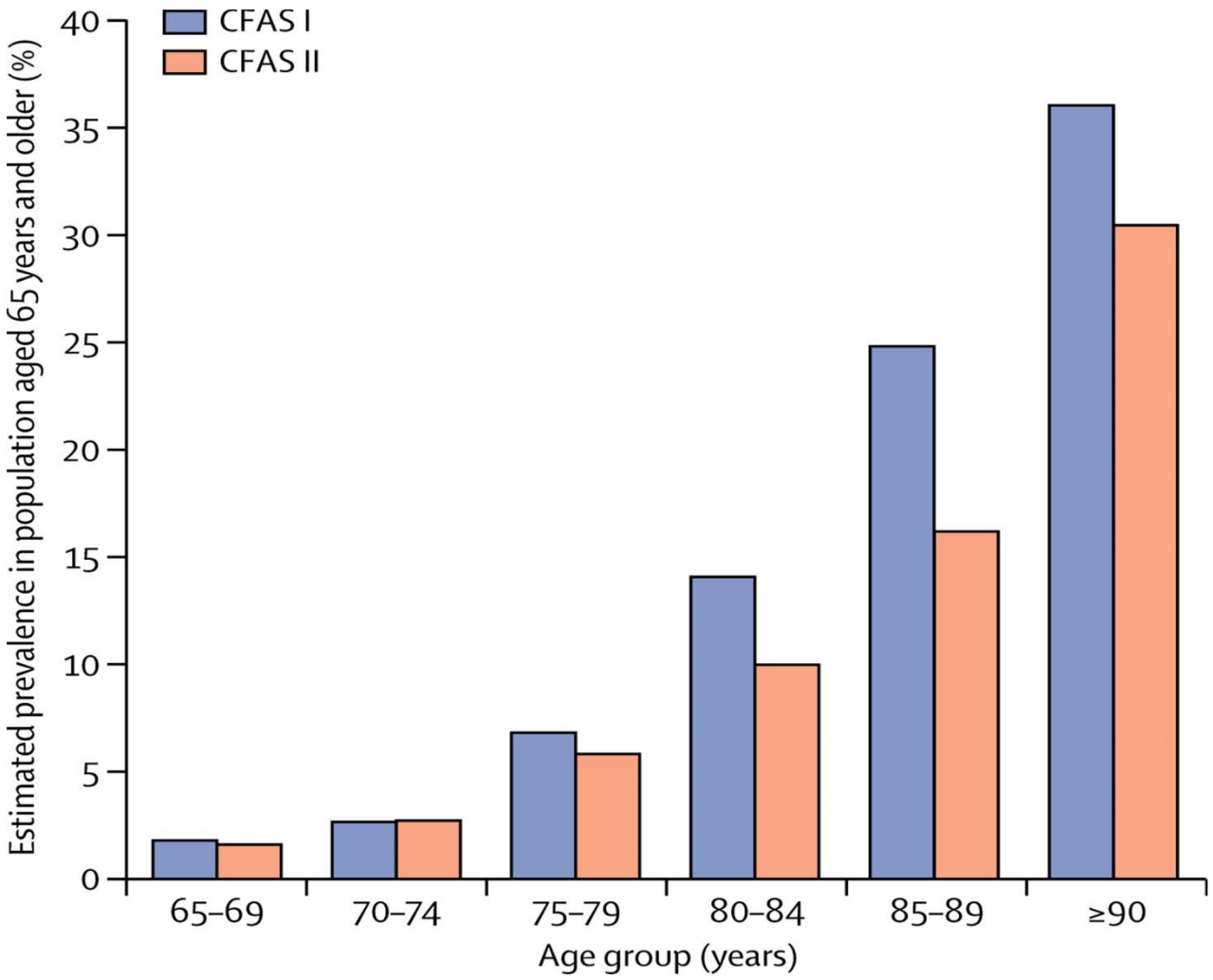
Good news on dementia prevalence—we can make a difference

Sube Banerjee [a]

The findings of the Cognitive Functioning and Ageing Study (CFAS) I and II are unequivocally good news. New data, reported in *The Lancet*,[1] suggest that the prevalence of dementia in the UK in 2011 was significantly lower than would have been expected based on the estimated prevalence in 1991. For CFAS I, data were taken from three geographical areas—Cambridgeshire, Newcastle, and Nottingham—to generate an estimate of the prevalence of dementia in the UK in 1991. This was based on a

CFAS I and CFAS II age-specific dementia prevalence



The Lancet 2013; 382:1405-1412

Lucia Dedear

daughter and unpaid Carer for father with Vascular Dementia

MODEM Project Launch
Thursday, 15 May 2014

Impact of Vascular Dementia

December 2008, Lucia and daughter move to England from Western Australia and husband, Bill, remains in Australia

Lucia

- family separated
- loss of full-time employment
- sell home
- friends
- lifestyle
- full responsibility for father / guardian
- full responsibility for daughter
- emotional
- mental & physical health

Husband

- family separated
- trying to support from Australia
- concern for daughter
- emotional

Father

- loss independence / capacity
- loss cognitive skills / mobility
- personality change
- less visits - siblings / friends
- incontinence
- loss of speech
- loss quality of life

Daughter

- family separated
- adjust to new country
- adjust to new school
- friends old /new
- lifestyle / culture
- emotional

Synopsis of Carer and Cared-for Pathway

2005
Death of wife / mother impact on Lucia and father

2006
Lucia aware all not well with father

2007
Father flood victim. Lucia goes to UK to help and sees father's GP

2007
GP refers for memory assessment & CT scan but inconclusive

2007/2008
Lucia takes father to Australia

2008 (Jan)
Father returns to UK. Signs of not coping, paranoia, depression and change of personality

2008 (Dec)
Lucia & daughter move into father's home to care for him

2008 (Dec)
Lucia notes a huge mental and physical change in her father

2009
Lucia & Father see GP. Refers to Mental Health provider

2009
Geriatric Psychiatrist treats father for depression

2009
Community Mental Health Nurse allocated

2009
(May) CT Scan diagnosed vascular dementia

2009
Nurse provides information and support

2009
GP refers to Adult Social Care

2009
Assessment for father - Care package. 14 hours per week

2009
ADSS agree respite for Lucia & daughter. Father in excellent residential home

2010
ADSS refuse request for respite in same residential home for father whilst Lucia & daughter return to Australia
Not listening to carer and BME needs of father

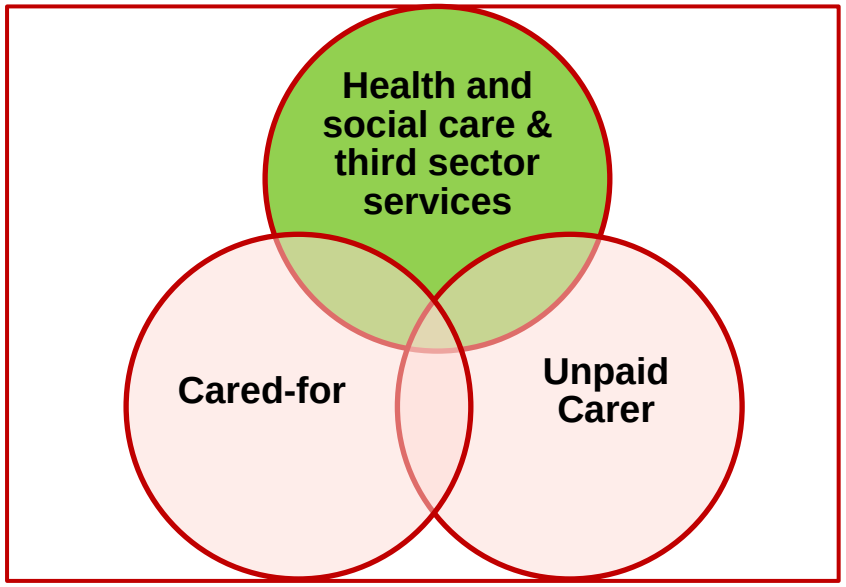
2010
ADSS re-assess father agree to permanent residential care but not taken up by daughter

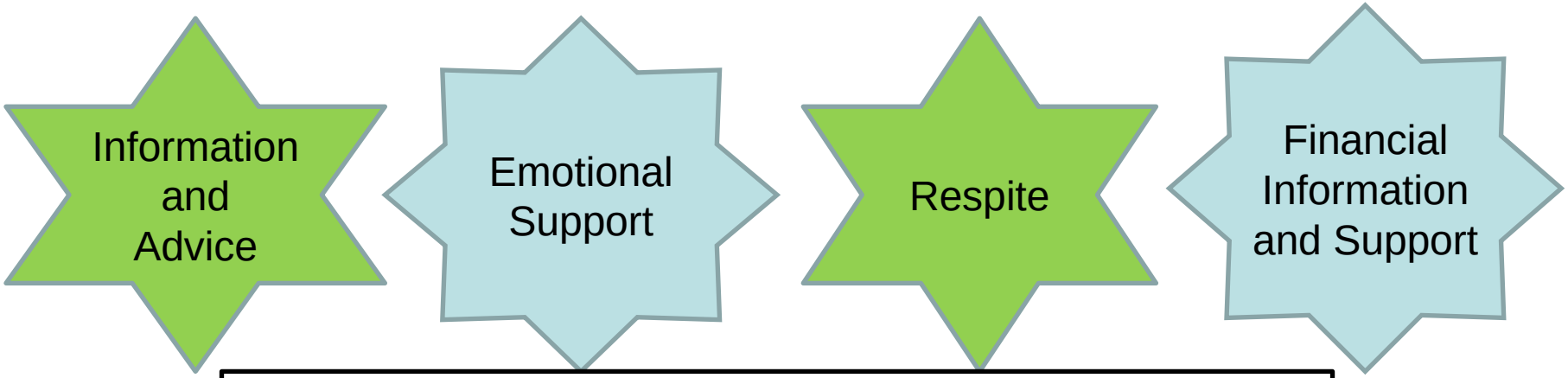
2011
Husband retires and joins family in UK. Helps to care for father-in-law

2012
Family unable to cope with father's advanced dementia. He moves into excellent residential home previously used for respite & meets his care and cultural needs

Triangle of Care & Co-production with Carer?

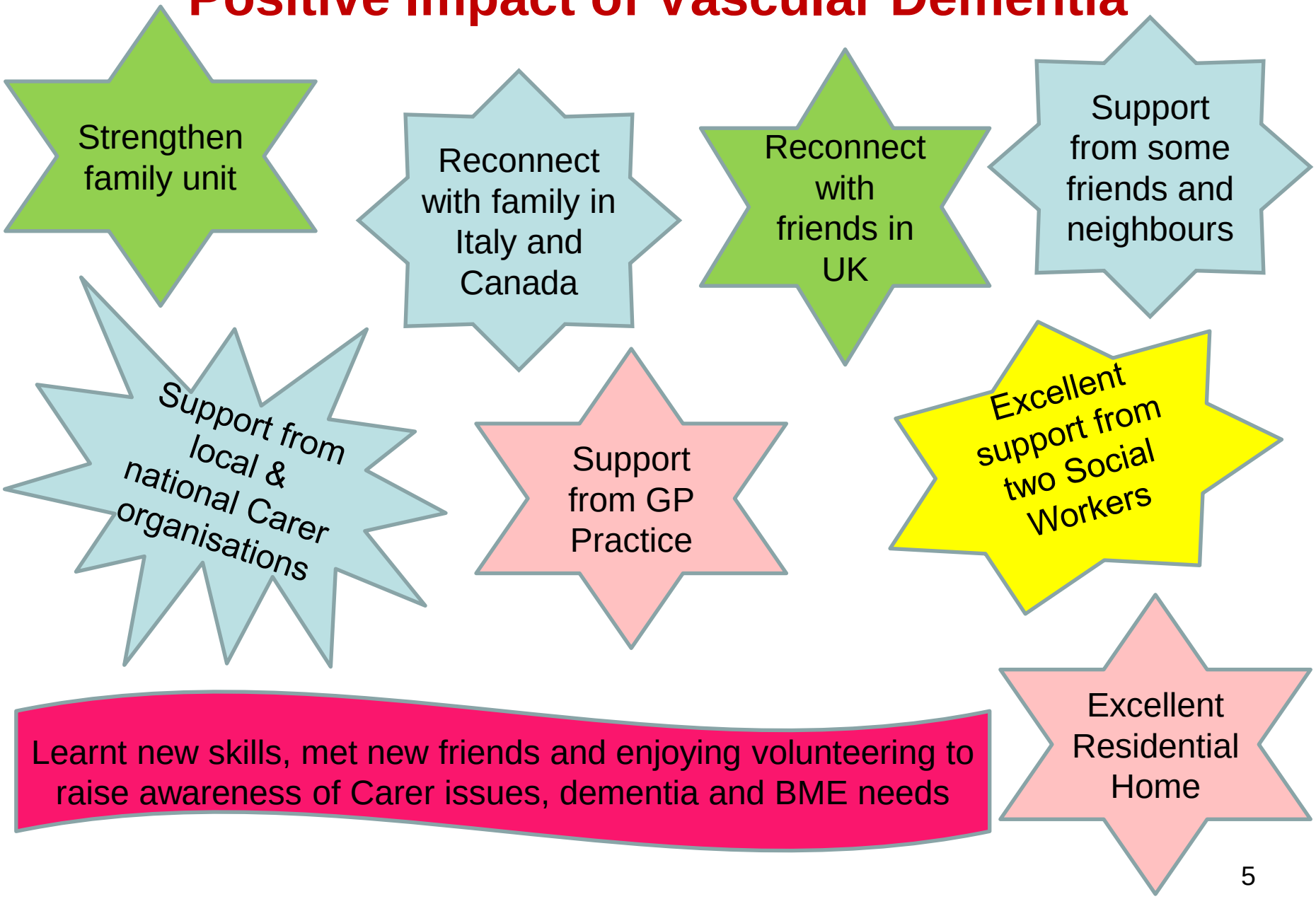
Impact of Vascular Dementia





Our class target is “to listen” carefully

Positive Impact of Vascular Dementia



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Grazie

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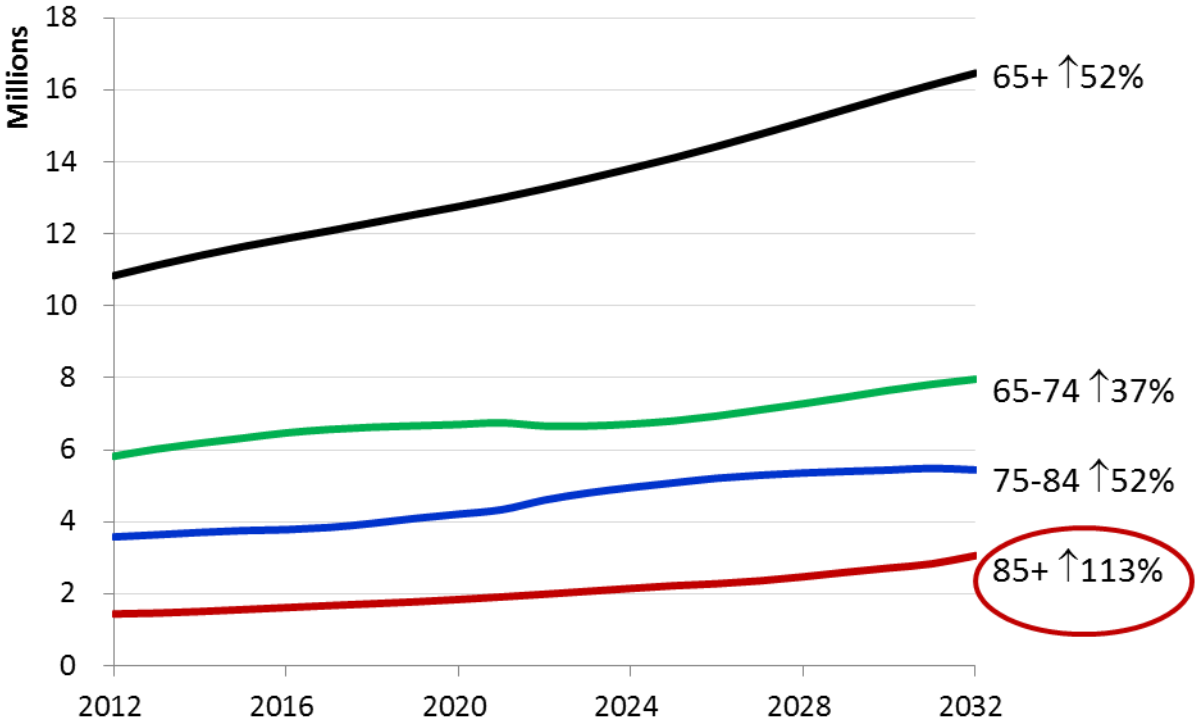
Ageing, comorbidity and care

Carol Jagger

AXA Professor of Epidemiology of Ageing

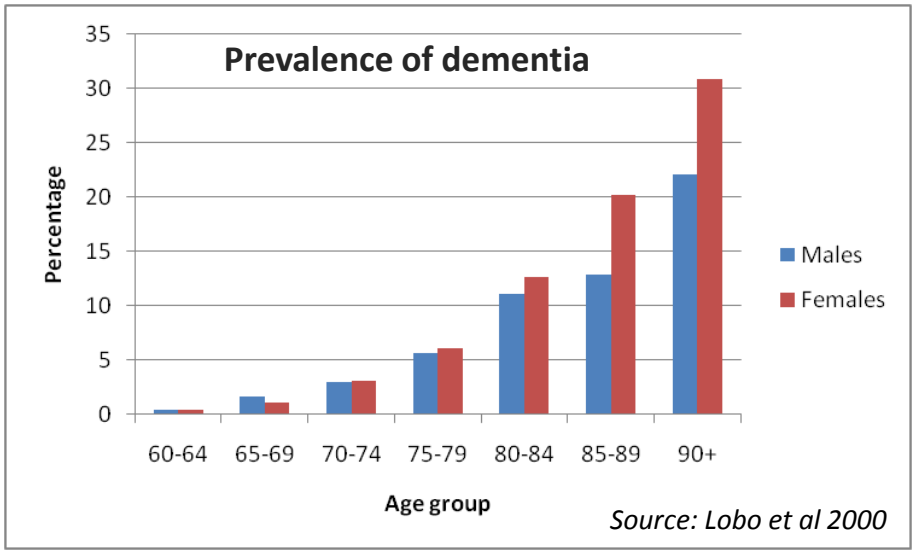
Institute for Ageing and Health, Newcastle University

Ageing populations – the challenges



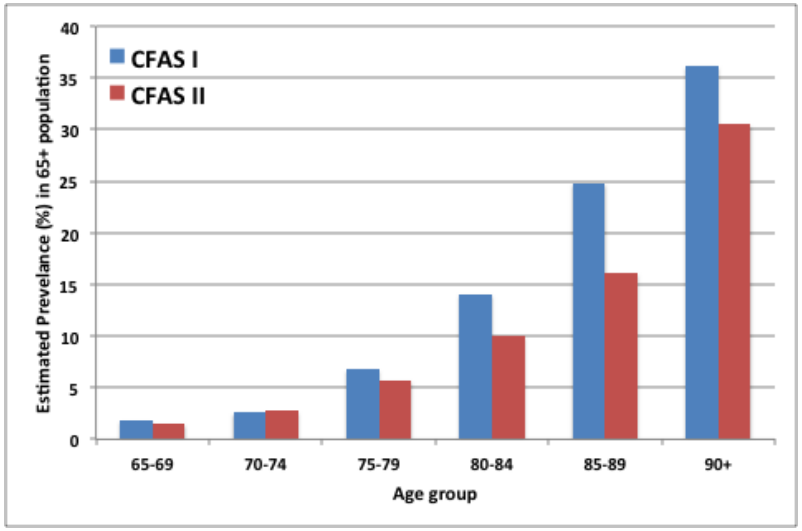
Prediction is very difficult, especially about the future.
Niels Bohr (1885 - 1962).

Implications for dementia



- Ready for Ageing report: 80% ↑ in numbers aged 65+ with dementia between 2010 and 2030

BUT

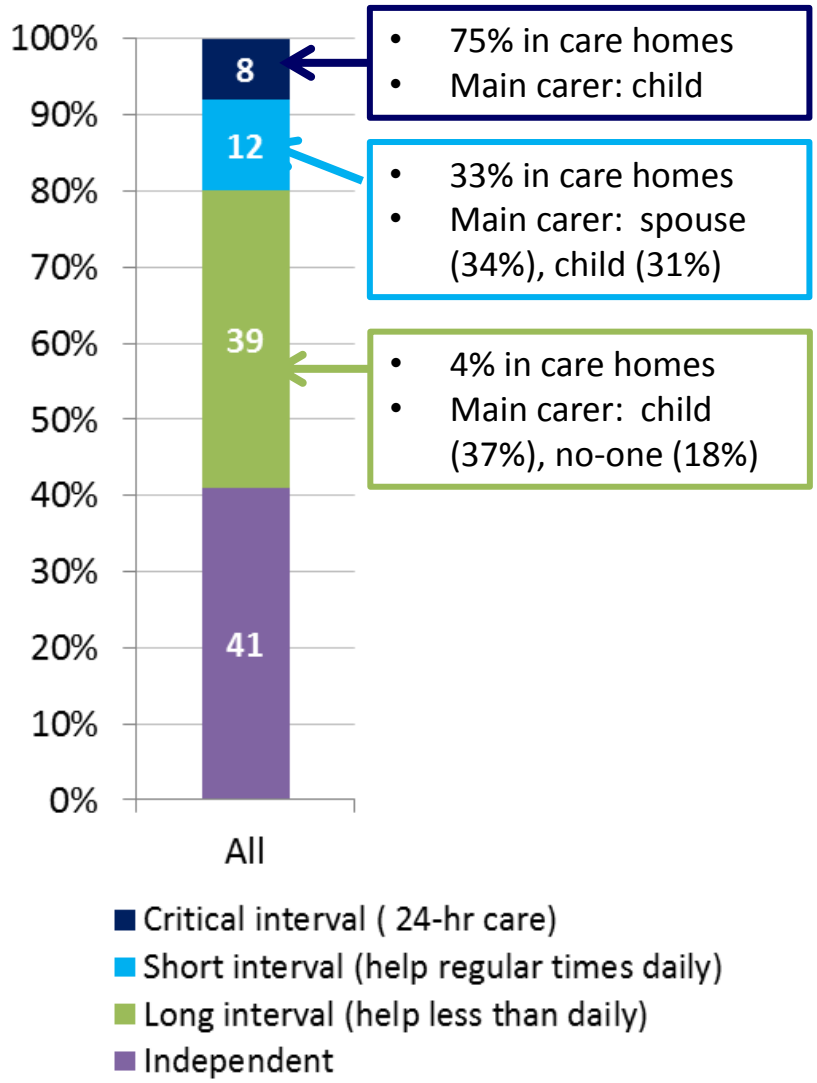


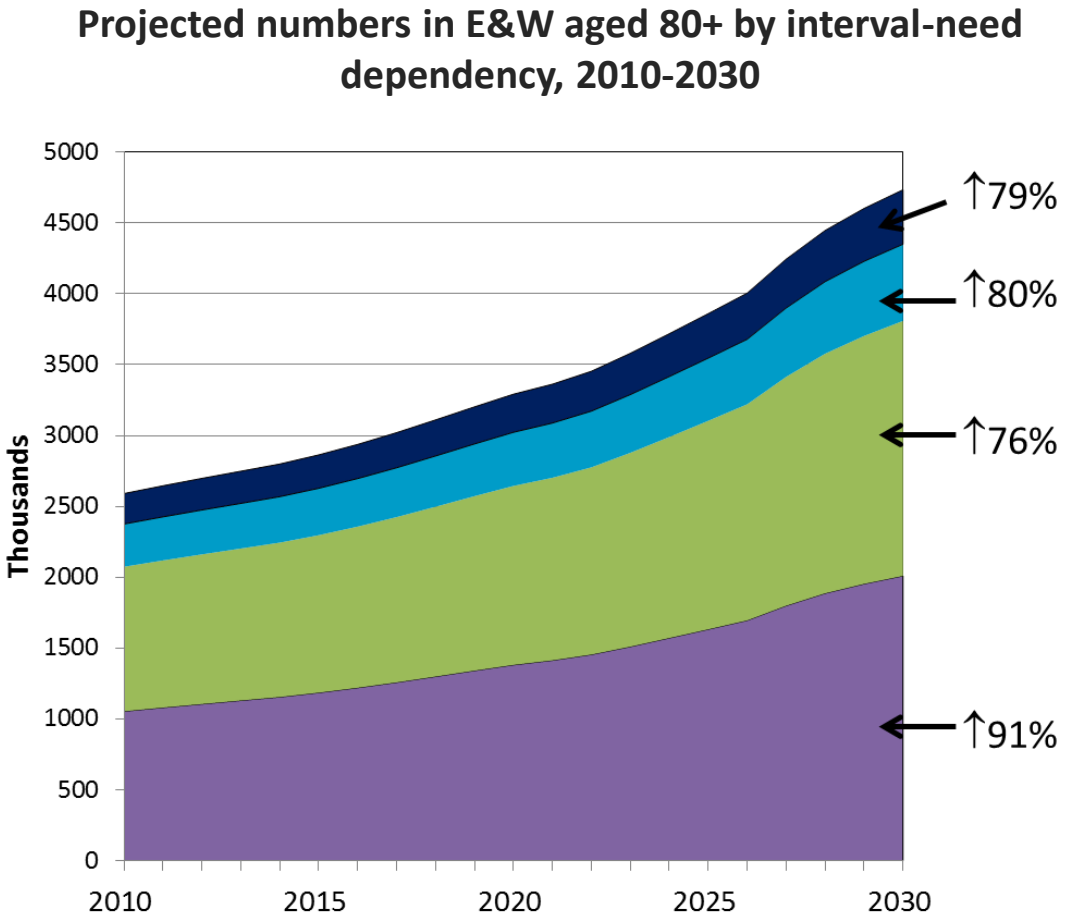
- Prevalence of dementia has <u>decreased</u> by 1.8%

A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II

Fiona E Matthews, Antony Arthur, Linda E Barnes, John Bond, Carol Jagger, Louise Robinson, Carol Brayne, on behalf of the Medical Research Council Cognitive Function and Ageing Collaboration

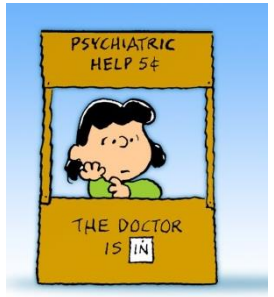
Implications for care needs

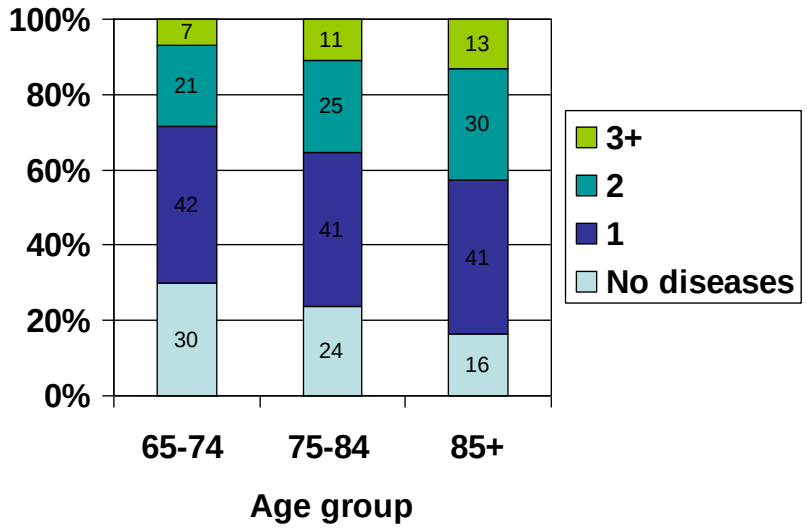




Source: Jagger et al (2011) BMC Geriatrics

Not just one disease





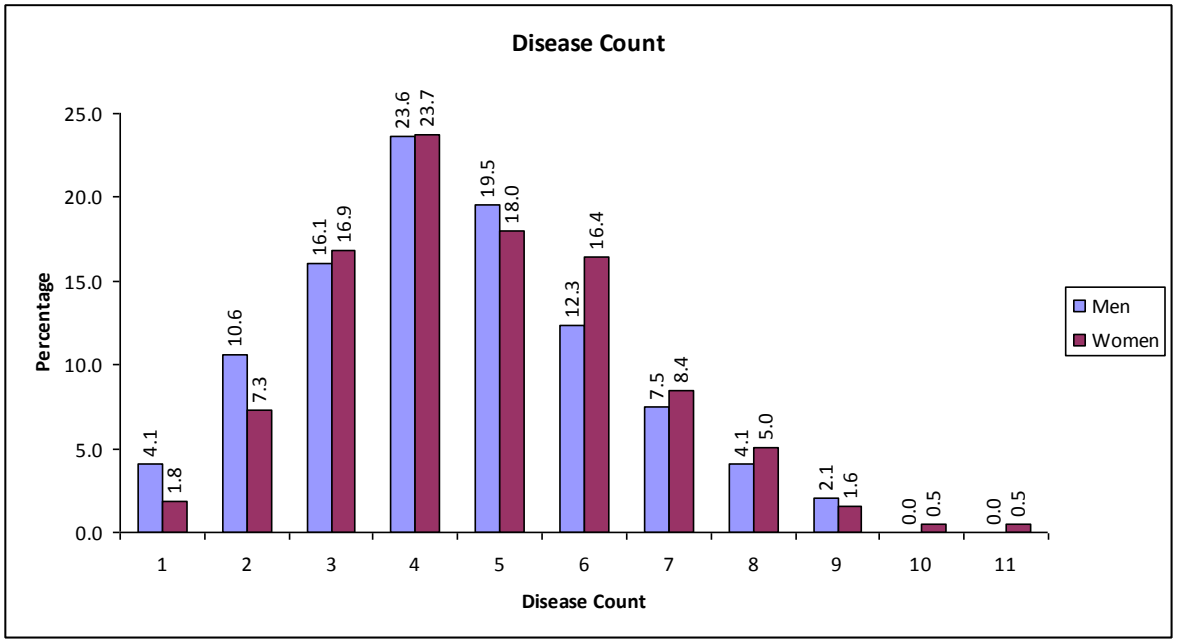
7 self-reported diseases: arthritis, stroke, CHD, chronic airways obstruction, peripheral vascular disease, cognitive impairment, diabetes

Source: MRC CFAS 1991

Median number of diseases:
Men = 4
Women = 5

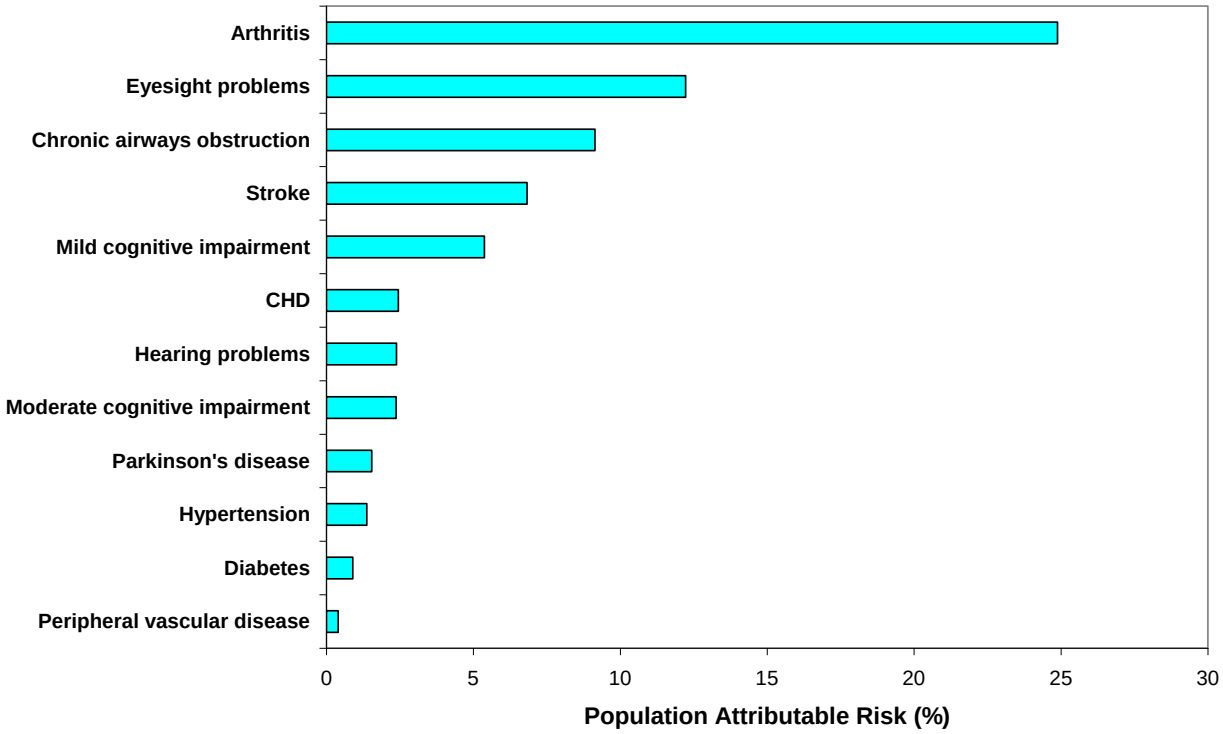
28% (men) and 32% (women) had 6+ diseases

Source: Newcastle 85+ Study 2006



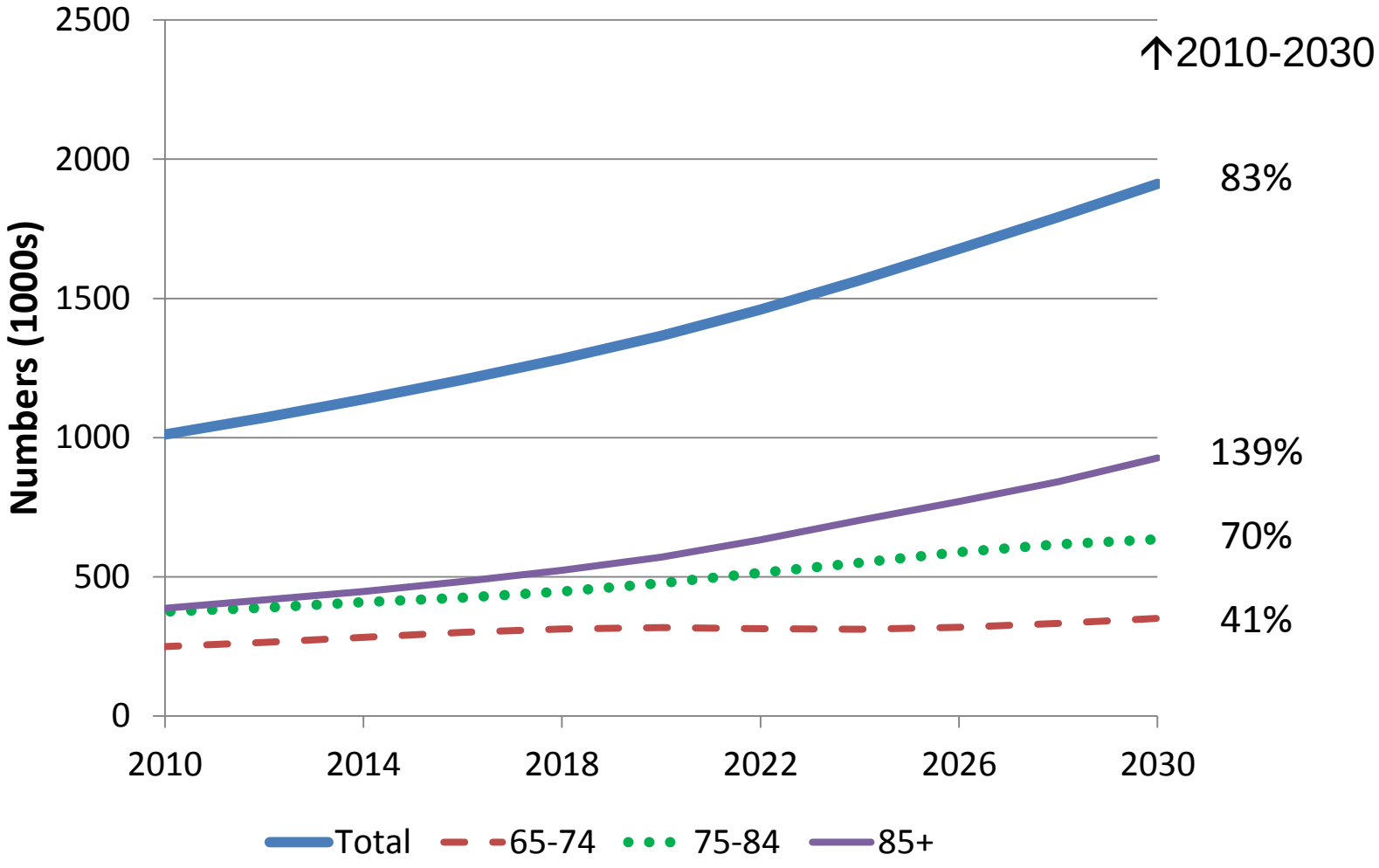
Why focus on disease?

- Disease is at the start of most models of the disablement process
- Major causes of disability in later life are: arthritis, CHD, dementia, stroke, sensory problems
- Substantial reductions in mortality from CHD and stroke have occurred
- Increases in obesity projected to continue: impact on CHD, stroke, arthritis, vascular dementia, diabetes



- Need to take into account multiple diseases as care needs for dementia will depend on comorbidities

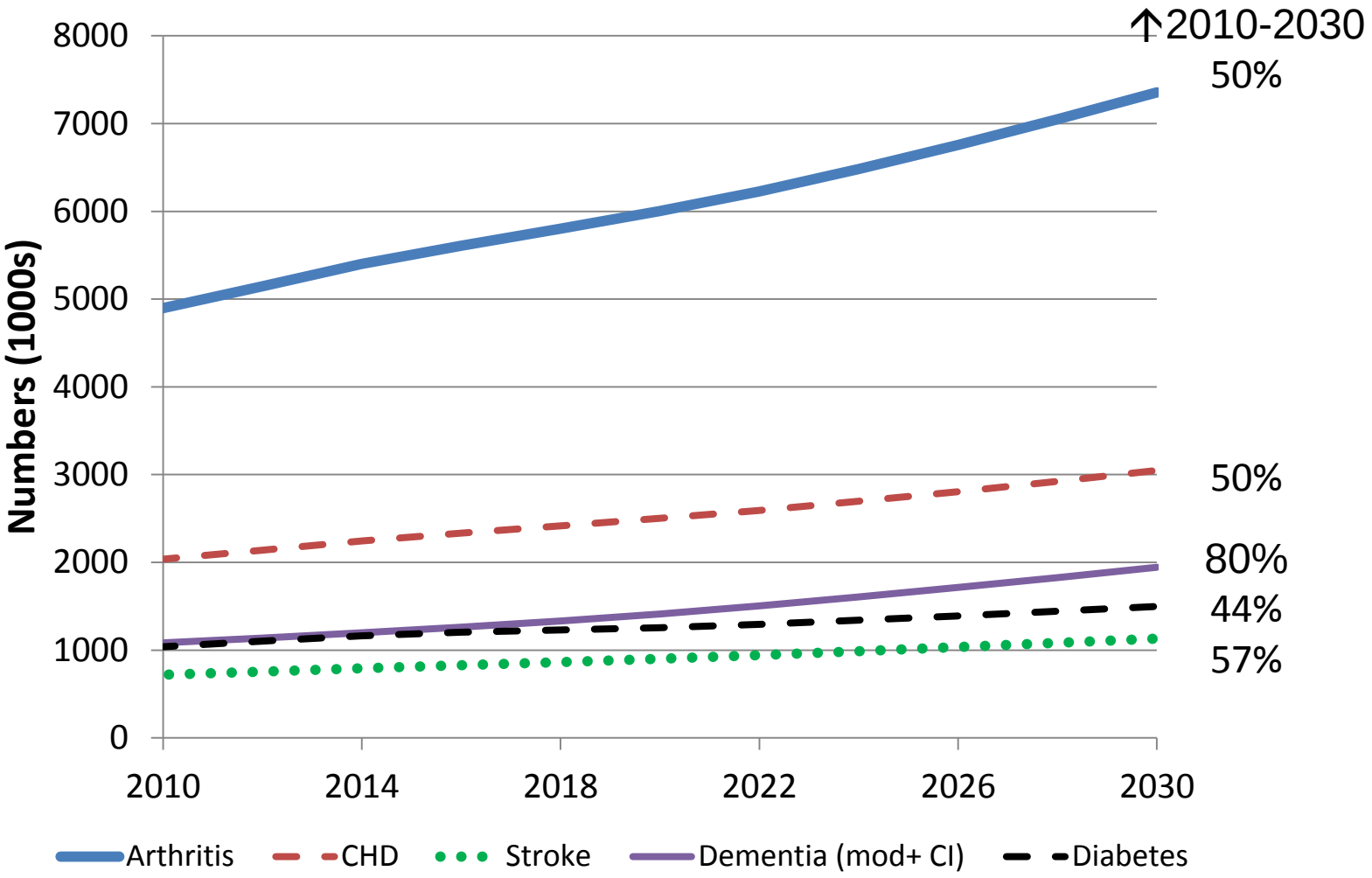
Numbers with disability 2010-2030



SIMPOP: Central Health Scenario (population ageing only)

MAP2030
Modelling Ageing Populations to 2030

Numbers with key diseases 2010-2030



SIMPOP: Central Health Scenario (population ageing only)

MAP2030
Modelling Ageing Populations to 2030

Summary - what we know

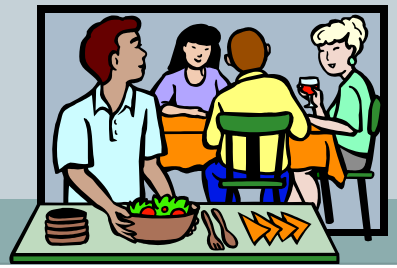
- Numbers of very old WILL increase
- Multiple diseases are the norm for the very old
- Care packages for and costs of dementia will be affected by comorbidities
- Main carers of very old are children – implications for extending working life and costs for families and society
- Ethnic minorities will form larger part of older population in future

Life course social interaction & participation:

Associations with cognitive function & use of services in later life

Emily Grundy Ann Bowling






Background

Physical and mental health in later life reflect outcomes of complex interactions between:

- early life circumstances including genetic and biological endowment,
- cumulative health behaviours,
- psychological characteristics,
- demographic & socio-economic circumstances,
- exposures to hazards/life course events
- social support and participation

Associations between social participation, social networks, and social support and later life physical and psychological health have been studied extensively; but previous literature on associations with cognitive function are inconsistent

Social interaction, cognitive function and use of services

Social interaction and cognitive function

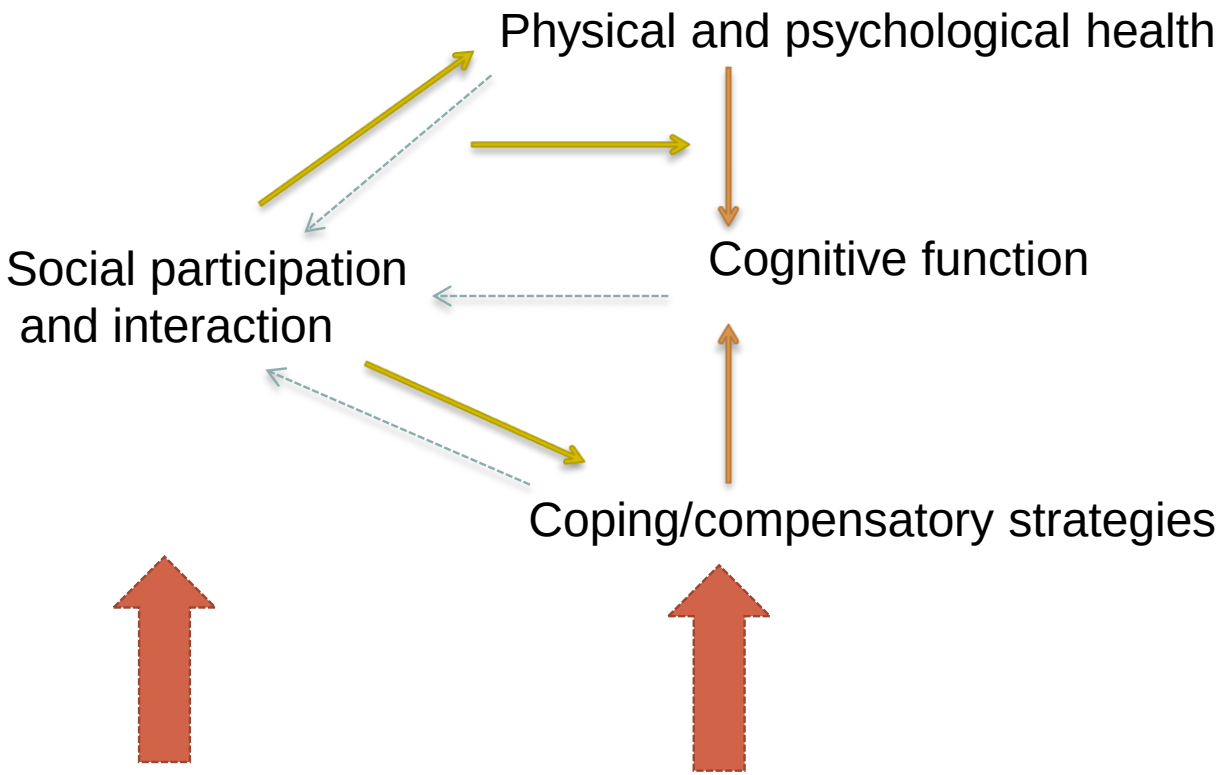
- Possible DIRECT effect of social interaction via mental stimulation
- Possible INDIRECT effect via better coping and compensatory strategies; stress buffering; physical health/health behaviours
- Possible REVERSE effect- cognitive decline may inhibit some social interactions (e.g. going out with friends) but promote other kinds (e.g. visits from concerned close family)

Social resources and sources of help for people with cognitive impairment:

- Accumulated social resources (family, friends, neighbours) a potential source of help for those with assistance needs due to cognitive decline- therefore might *reduce* needs for/use of formal services
- Accumulated social resources a potential source of help in seeking and accessing formally provided help-therefore might *increase* use of formal services

Many other factors may influence **both** social interaction and cognitive function, or the pattern of association between them – for example, early life circumstances and genetic and biological endowment; personality; education; socio-economic status; availability of spouse and children; neighbourhood etc –these need to be taken into account.

Hypothesised associations between social interaction and cognitive function



Research questions

- Are patterns of social interaction and participation associated with cognitive functioning in early and later older age?
- Is the type of interaction/participation important?
- Is the trajectory of participation important?
- What are the effects of accumulated social support networks on coping strategies of older people with cognitive impairment, including:
  - access to help from family and friends
  - seeking and accessing formally provided services

Data

- Life course data set: National Child Development Study (NCDS) has followed people born in one week in 1958; most recent sweep in 2013.
- Later life multi-cohort study of people aged 50 and over: English Longitudinal Study of Ageing (ELSA) wave 1 2002; subsequent waves every two years (wave 6 available shortly).
- Both used the same measures of cognitive functioning: word list recall, animal naming, letter cancellation, delayed word list recall (NCDS at ages 16 & 50; ELSA waves 1-5)
- A range of measures of social & family relationships, activities, social & civic participation collected at different points of the lifecourse
- Also detailed information on other variables relevant to social participation and to health and cognitive function (childhood health, attainment, behaviour and family circumstances; education and lifelong learning; occupation; income & wealth; partnership and children; health related behaviours etc).

Analysis

- Outcome variables: cognitive functioning at age 50 (NCDS) & trajectories of cognitive functioning after age 50 (ELSA); sources of support and use of services among those with cognitive impairment (ELSA).
- Multi-variable models of sequential changes to examine any effects of changes in predictor variables on cognitive functioning (from analyses of basic change variables by waves to cross-lagged temporal regressions);
- Structural equation modelling to examine mediators and moderators
- Requires careful formulation of explicit models of the processes, ensuring controls for potential influencing variables.
- Multiple imputation methods to take account of missing data

Outputs

- Results used to inform modelling of projected dementia, costs & affordability of preventive levels of social interaction & participation, dynamics of service supply

- Substantive and methodological papers for publication

MODELLING FUTURE COSTS OF LONG-TERM CARE

Raphael Wittenberg
and Colleagues
Personal Social Services Research Unit
London School of Economics and Political Science

Modem Launch Event 15 May 2014

ACKNOWLEDGEMENTS

- Funders: Department of Health, UK Research Councils, Alzheimers Research Trust, AXA Research Fund and others
- Research Team: Adelina Comas-Herrera, Jose-Luis Fernandez, Bo Hu, Derek King, Juliette Malley, Linda Pickard and colleagues
- Collaborations: University of East Anglia, University of Newcastle and others

POLICY CONTEXT FOR LONG-TERM CARE FINANCE

Concern over future affordability of long-term care for older people

- highly labour-intensive
- potentially rising expectations
- increasing numbers living to late old age
- uncertainty over numbers who will need care

Debate about the fiscal sustainability of long-term care funding and the appropriate balance between public and private funding

PSSRU LONG-TERM CARE FINANCE PROJECTIONS MODELS

- Projections for disabled older people, for Royal Commission, Department of Health, Wanless Commission, Dilnot Commission etc, exploring different financing systems
- Projections for cognitive impairment, for Alzheimers Research Trust, exploring impact of changing prevalence and patterns of care
- Projections for younger adult groups, for Department of Health, Dilnot Commission

LONG-TERM CARE

- Informal care: Unpaid care by family and friends, especially spouses and adult children
- Social services: Formal home-based services and residential care services
- Health services: Community nursing and therapy services
- Social security: Disability benefits (cash)

PSSRU MACRO MODEL

This produces projections of:

- Numbers of disabled older people
- Numbers of older users of informal care, formal care services and disability benefits
- Public and private expenditure on long-term care (long-term health and social care)
- Workforce providing social care

DRIVERS OF DEMAND FOR CARE

- Life expectancy and mortality rates
- Disability rates - compression or expansion of morbidity and disability
- Household composition and informal care
- Unit costs of care such as the cost of an hour's home care
- Public expectations about long-term care

BASE CASE ASSUMPTIONS FOR PROJECTIONS

- Number of people by age, gender and marital status changes in line with official projections
- Prevalence rates of disability by age and gender remain unchanged (except for learning disability)
- Unit costs are constant to 2015/6 and then rise by 2.0% per year in real terms
- Patterns of care – formal and informal – and the funding system remain unchanged

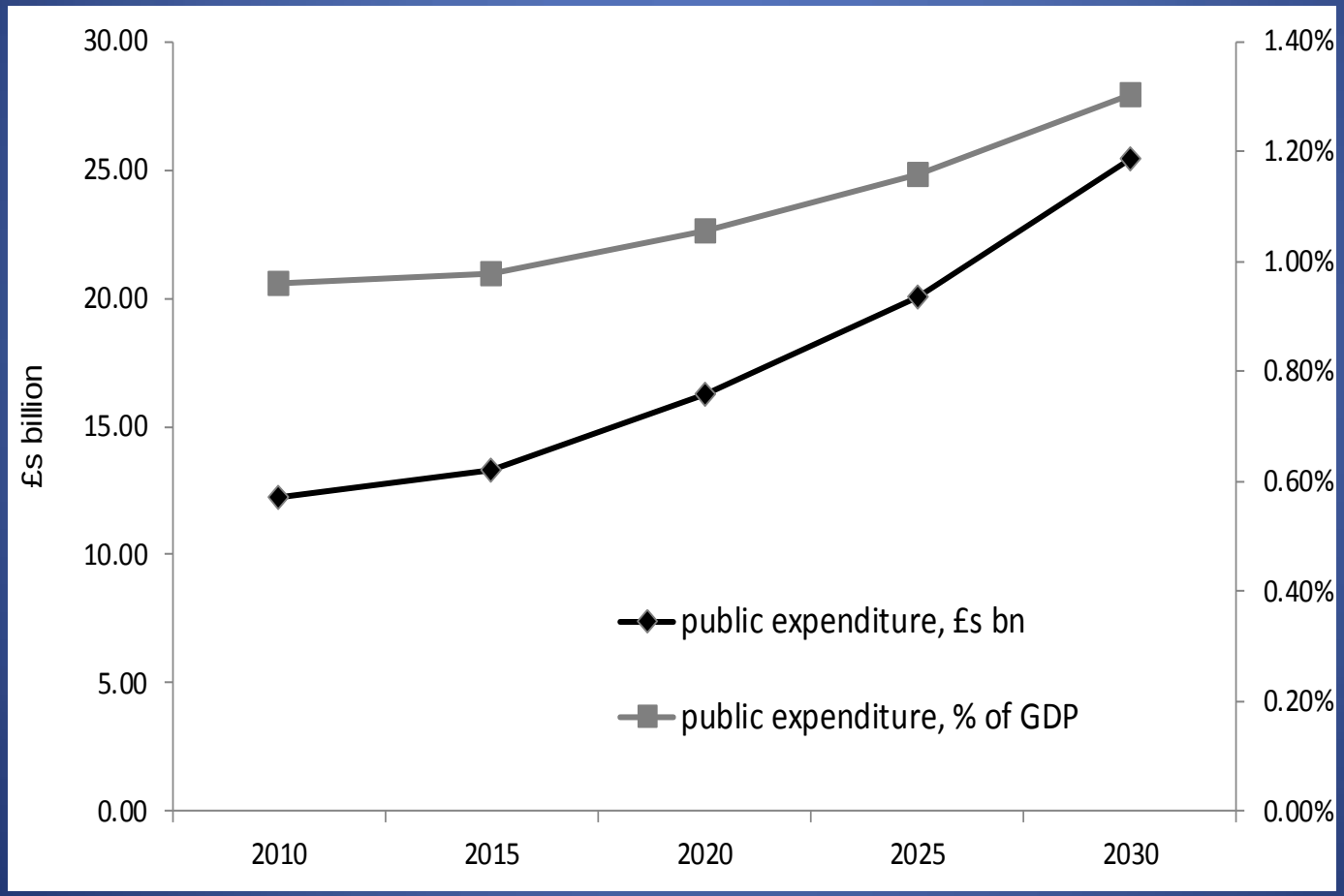
DEMAND PRESSURES, OLDER PEOPLE IN ENGLAND, 2010 TO 2030

- The number of disabled older people is projected to rise by 59% between 2010 and 2030 (from 1.0 in 2010 to 1.6 million in 2030)
- This is sensitive to assumptions about future mortality and disability rates
- The number of older users of care services would need to rise by 63% between 2010 and 2030 to keep pace with demographic pressures
- A higher rise would be required if unpaid care by children did not rise in line with demand

PROJECTED PUBLIC EXPENDITURE ON LONG-TERM CARE FOR OLDER PEOPLE, 2010 TO 2030

- Public expenditure in England on long-term health and social care for older people and on disability benefits used towards care costs is estimated to be £12 billion in 2010
- It is projected to more than double by 2030, to £25.5 billion in 2010 prices, to keep pace with demographic and economic pressures
- This would be a rise from around 0.95% of GDP in 2010 to 1.3% of GDP in 2030

PROJECTED PUBLIC EXPENDITURE ON LONG-TERM CARE FOR OLDER PEOPLE, ENGLAND, 2010 TO 2030



FURTHER INFORMATION

Please see our website www.pssru.ac.uk

MODEM

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

Martin Knapp

MODEM

A collaborative study

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- Sube Banerjee

International Longevity Centre-UK

- Sally-Marie Bamford
- Sally Greengross

MODEM

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.

MODEM

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?

MODEM

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

MODEM

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)

MODEM

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

MODEM

Empirical models

- Dynamic micro-simulation projection model on disabling consequences of dementia
- Care pathways model of how interventions impact on service use and costs
- Macro-simulation projection model of long-term care need and costs under different scenarios

MODEM

What goes into the models?

- Evidence / learning from previous models
- Large-scale datasets (CFAS II, ELSA, NCDS)
- Previous studies (hence literature review)
- Completed and ongoing trials
- Data on dementia & social participation/ isolation
- ‘Cross-walking’ study of 300 people with dementia and their carers
- Focus groups with people with mild dementia and carers
- Inputs from our advisory and user, carer and practitioner reference groups

MODEM

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.

MODEM

How can you help?

- Tell us if you'd like to be involved in one of our groups (Advisory / Reference / Focus) and we will see if we can accommodate you.
- Tell us about any new developments in the area that you think are relevant – new interventions etc
- Be our critical friends!

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Contact us

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Project webpage on LSE website to follow soon

Thanks!

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