MODEM

modelling outcome and cost impacts
of interventions for dementia

15 November 2018
The Lincoln Centre, 18 Lincoln's Inn Fields, London WC2A 3ED

10:30	Arrival, refreshments served	
11:00	Welcome from Chair	James Pickett (Alzheimer's Society)
11:05	Introduction to MODEM	Martin Knapp (LSE)
11:15	Baseline data from the MODEM cohort: quality of life and severity of dementia	Sube Banerjee (Sussex)
11.30	Change over time in quality of life and cost of care of people living dementia – Analysis of the MODEM cohort	Derek King (LSE)
11.45	Q&A	
11.55	Mapping the dementia care pathway in England	Adelina Comas-Herrera (LSE)
12.10	Projections of care needs and the contribution of dementia	Carol Jagger (Newcastle)
12.25	Q&A	
12.35	Lunch	
13.05	Projections of costs of care for older people living with dementia	Raphael Wittenberg (LSE)
13.20	Scaling up evidence-based interventions: benefits and costs to 2040	Martin Knapp (LSE)
13.35	Q&A	
13.45	Rapid fire: • Social isolation predicts memory decline in older age • Measuring unpaid care hours • Well-being of unpaid carers of people with dementia: why carer age and gender matter • Economic evaluation and dementia: state of the art • The MODEM legacy model • The MODEM Reference Group of Users and Carers	Sanna Read (LSE) Amritpal Rehill (LSE) Klara Lorenz (LSE) David McDaid (LSE) Raphael Wittenberg (LSE) Margaret Dangoor (LSE)
14.15	Panel discussion	Carol Brayne (Cambridge) Matt Norton (Alzheimer's Research UK) Chris Roberts ((MODEM RGUC)) Barbara Witzenfeld (MODEM RGUC)
14.50	Closing remarks	Martin Knapp (LSE) James Pickett (Alzheimer's Society)
15.00	Close	

MODEM

Final Conference

15 November 2019

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Introduction to MODEM

Martin Knapp

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ES/L001896/1

ES/L001896/1 Comprehensive approach to modelling outcome and cost impacts of interventions for dementia

… aka **MODEM**

One of six ‘dementia projects’ funded jointly by:

- Economic and Social Research Council (ESRC)
- National Institute for Health Research (NIHR)

MODEM started March 2014 and ends … very soon

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MODEM: core research questions

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

Research team

London School of Economics and Political Science (PSSRU): Martin Knapp, Adelina Comas-Herrera, Raphael Wittenberg, Bayo Adelaja, Annette Bauer, Margaret Dangoor, Jackie Damant, Josie Dixon, Bo Hu, Daniel Lombard, Klara Lorenz, David McDaid, A-La Park, Sanna Read, Amritpal Rehill

LSE (Social Policy Department): Emily Grundy (now Univ. of Essex)

Newcastle University: Carol Jagger and Andrew Kingston

Southampton University: Ann Bowling (now retired), Jitka Pikhartova (now Brunel Univ.)

Sussex University (Brigton and Sussex Medical School): Sube Banerjee, Nicolas Farina with research assistance from: Sharne Berwald, Clare Burgon, Elizabeth Bustard, Ruth Habibi, Yvonne Feeney Laura Gallaher

International Longevity Centre UK: Sally Greengross

Reference group of users & carers

Toni Battison
Karen Block
Maria Boyd
Louise Capitelli
Stella Chattle
Carol Fordyce
Jane Goodrick
Shamime Lakda

Bernadette Menasse
Batcho Notay
Jaquie Nunn
Chris Roberts
Elizabeth Sallis
Barbara Witzenfeld
John Witzenfeld

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Advisory group

Nick Black, LSHTM (chair)
Charles Alessi, PHE
Carol Brayne, Univ Cambridge
Alistair Burns, Univ Manchester
Bob Butcher, DHSC
Margaret Dangoor, RGUC rep
Martin Green, Care England
Joanne Goddard, ESRC
Karen Harrison-Dening, DUK

Jill Manthorpe, KCL
Kayleigh McNamara, PHE
Matt Norton, ARUK
David Pearson, Notts CC
James Pickett, Alz Society
Marcus Richards, UCL
Martin Rossor, UCL
Allison Smith, C for AB
Wendy Weidner, ADI

Study components

A. Engage with **people with dementia, carers**, other stakeholders

B. Map **extant evidence** on effectiveness & cost-effectiveness

C. Collect data from **cohort of people with dementia & carers**

D. Describe **care pathways** for people with dementia & carers

E. Estimate **current cost of dementia** in England

F. Project **dependency consequences** (microsimulation (*PACSim*))

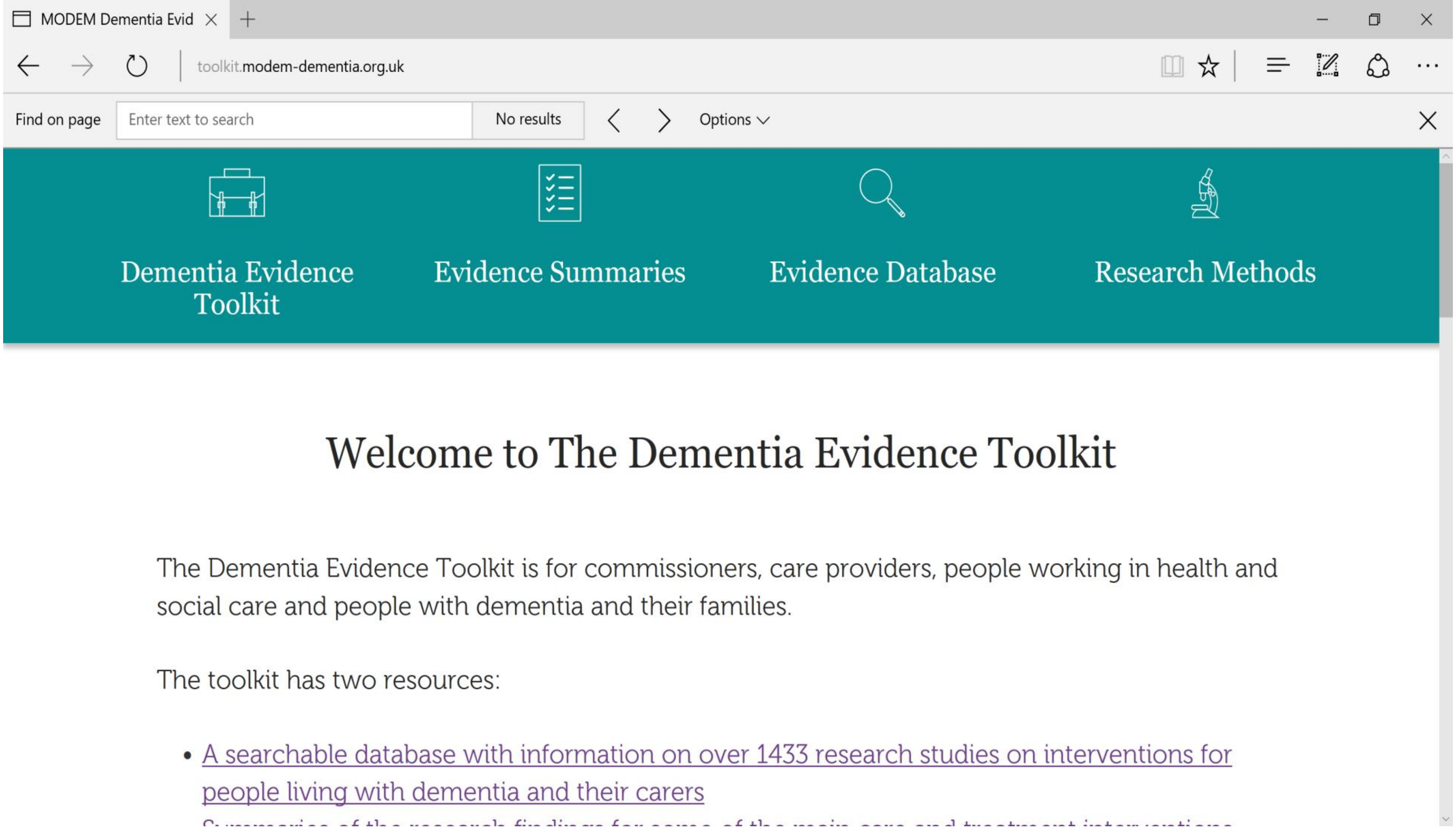
G. Project **needs, costs & QOL** (macrosimulation)

H. Explore **carer roles & wellbeing by age/gender** - attached PhD

I. Model **scaled-up interventions**: future costs & outcomes

J. Leave something behind: **MODEM Legacy model**

Dementia Evidence Toolkit



Welcome to The Dementia Evidence Toolkit

The Dementia Evidence Toolkit is for commissioners, care providers, people working in health and social care and people with dementia and their families.

The toolkit has two resources:

- A searchable database with information on over 1433 research studies on interventions for people living with dementia and their carers

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Baseline data from the MODEM cohort: quality of life and severity of dementia

Sube Banerjee, Nicolas Farina, Derek King, Adelina Comas-Herrera, Martin Knapp

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ilc... International Longevity Centre UK

Purpose

- New cross-sectional and longitudinal data collected from fieldwork
- **Primary purpose** to feed MODEM models with cross-walked data:
  - across dementia severity
  - between instruments
  - cross-sectionally
  - changes over one year
- Data fed into other work packages including, micro-simulation projection models and macro-simulation projection models.
- **Secondary purpose** to generate a better understand the impact of dementia severity on outcomes, including quality of life

- **This presentation** to summarise
  - The cohort study methodology
  - New data on the impact of dementia severity on the quality of life of people with dementia and their carers cross-sectionally

Recruitment

- Cohort of **300 dyads**: people living with dementia and their principal carer
- Target of 100 each with mild (20+ on sMMSE), moderate (10-20 sMMSE) and severe dementia (0-9 sMMSE).
- Recruited from South East England, predominately Sussex
- Interviewed at **baseline and 52 week** follow-up

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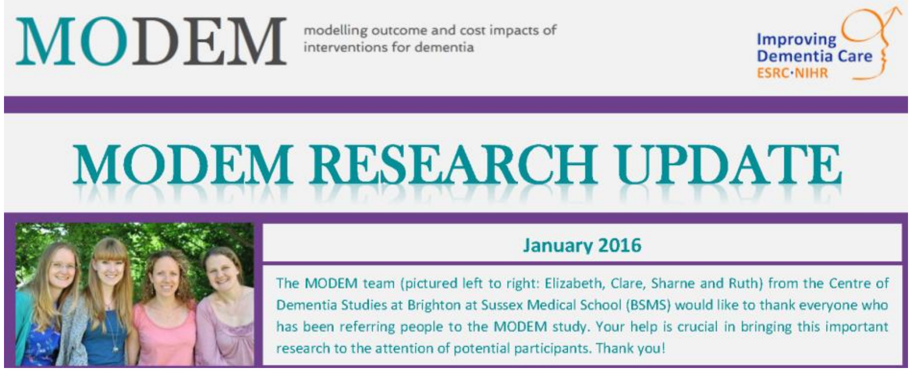
Recruitment strategy

- Clinician referrals from Sussex Partnership NHS foundation Trust
- Join Dementia Research
- Self-referrals via posters and flyers



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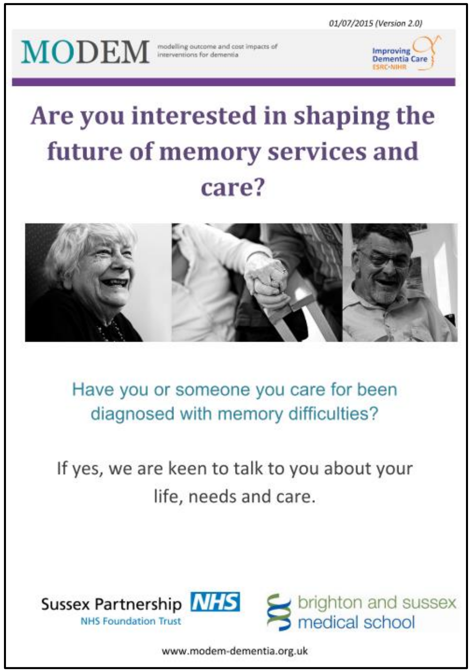
MODEM RESEARCH UPDATE

January 2016

The MODEM team (pictured left to right: Elizabeth, Clare, Sharne and Ruth) from the Centre of Dementia Studies at Brighton at Sussex Medical School (BSMS) would like to thank everyone who has been referring people to the MODEM study. Your help is crucial in bringing this important research to the attention of potential participants. Thank you!

Join dementia research



01/07/2015 (Version 2.0)

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Are you interested in shaping the future of memory services and care?

Have you or someone you care for been diagnosed with memory difficulties?

If yes, we are keen to talk to you about your life, needs and care.

Sussex Partnership NHS Foundation Trust

brighton and sussex medical school

www.modem-dementia.org.uk

Measures

- Person with dementia
  - Cognition
  - Quality of life
  - Neuropsychiatric symptoms
  - Activities of daily living
  - Social resources
  - Health

- Carer
  - Quality of life
  - Carer burden
  - Health
  - Support received

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Measures - person with dementia

- sMMSE
- ADAS-COG
- ELSA cognitive function module

- DEMQOL
- EQ5D
- CASP-19
- Personal well-being scale

- Relationship Quality Questionnaire
- Disease insight Scale
- Social Isolation Scale
- Physical Activity Stages of Change Questionnaire

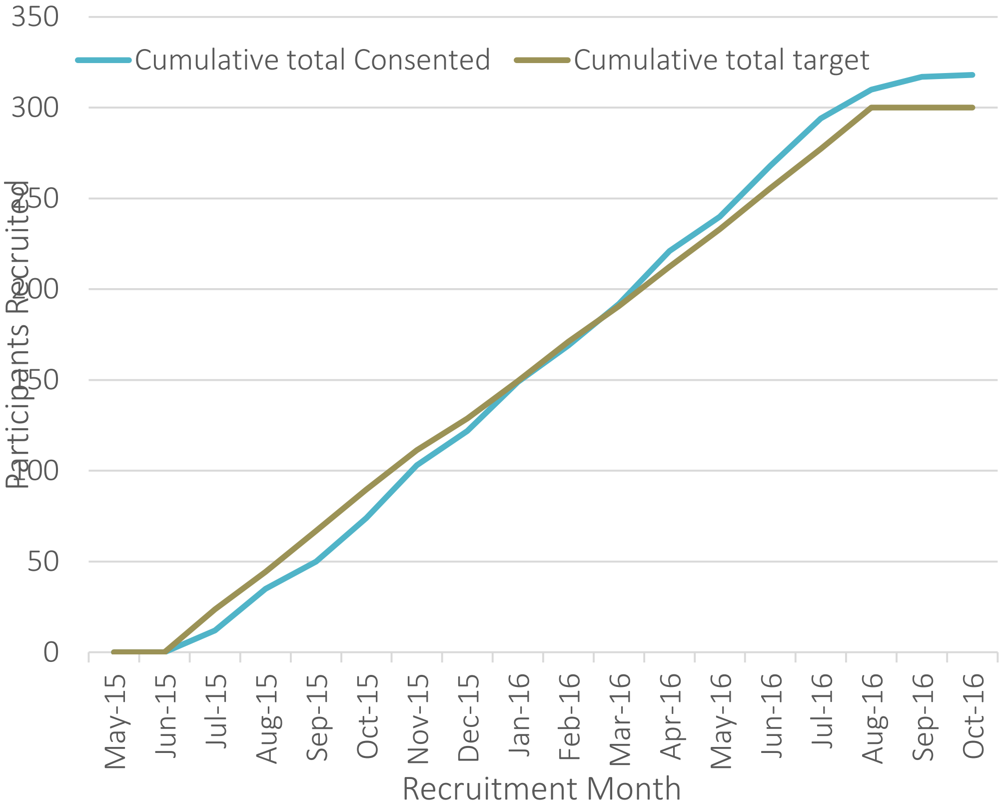
Measures - carer

Carer on Person with Dementia

- DEMQOL-Proxy
- EQ5D
- NPI
- BADL
- CSRI
- CCI
- CSDD

Carer on Self

- GHQ-12
- EQ5D
- SF-12
- ZCBI
- Social Isolation Scale
- Personal well-being scale

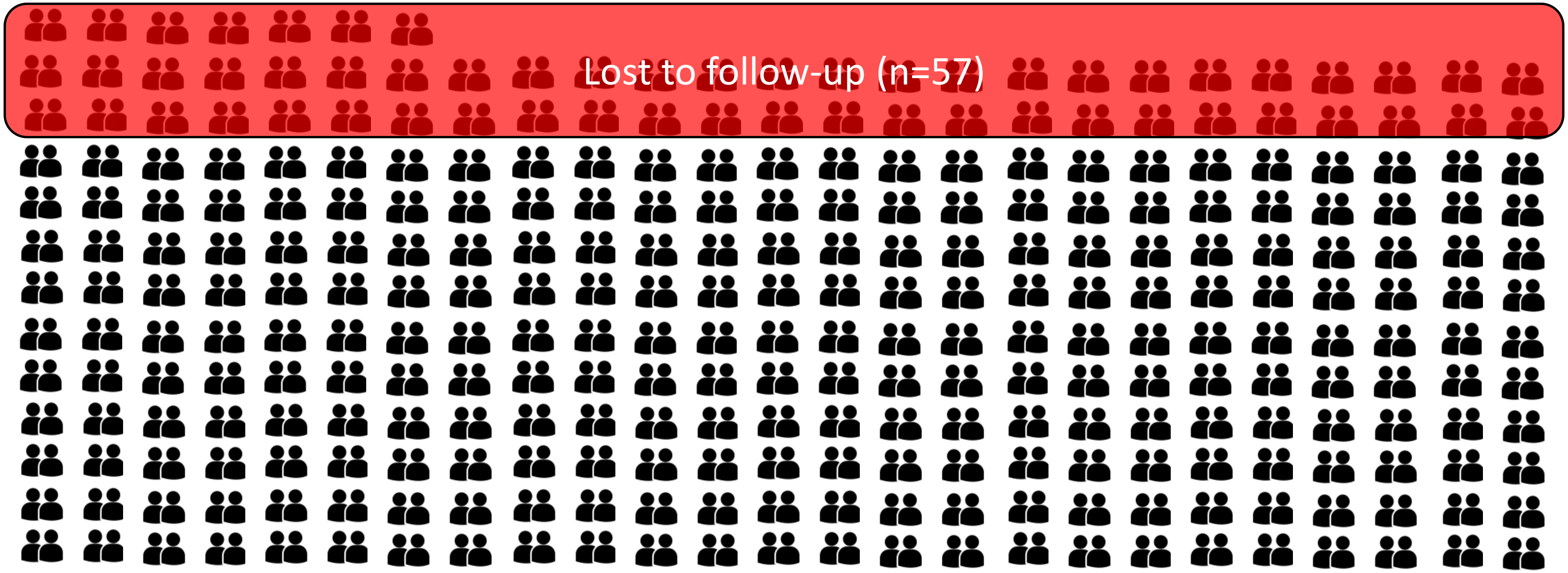


Recruitment

- Achieved target in August 2016

MODEM cohort

- 307 people with dementia and their primary carers
- 250 dyads were followed up (Derek King to discuss)



MODEM cohort

Person with dementia descriptive data by severity

	Mild		Moderate		Severe	
	Mean (SD)	N (%)	Mean (SD)	N (%)	Mean (SD)	N (%)
Age	80.2 (7.2)		82.4 (8.8)		80.0 (9.2)	
Male		62 (56.4%)		55 (55.6%)		34 (35.1%)
Living in care home		6 (5.5%)		17 (17.0%)		40 (41.2%)
White British		105 (96.3%)		88 (89.8%)		88 (90.7%)
Alzheimer's Disease		63 (63.0%)		55 (57.9%)		58 (61.1%)

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MODEM cohort

Carer descriptive data by severity

	Mild		Moderate		Severe	
	Mean (SD)	N (%)	Mean (SD)	N (%)	Mean (SD)	N (%)
Age	71.5 (12.0)		68.7 (11.4)		67.3 (10.6)	
Male		32 (29.4%)		26 (26.5%)		44 (45.4%)
White British		106 (98.1%)		90 (91.8%)		89 (94.1%)
Co-resident		87 (79.8%)		66 (67.3%)		50 (51.5%)
Spousal relationship		84 (76.4%)		60 (60.6%)		54 (55.7%)

Effect of severity

Person with dementia

Female
$\chi^2 = 11.62$, $p = 0.003$

Live in a care home
$\chi^2 = 41.59$, $p < 0.0001$

Cognitively impaired
$F = 1360.36$, $p < 0.0001$

Functionally impaired
$F = 66.03$, $p < 0.0001$

Neuropsychiatric symptoms
$F = 15.51$, $p < 0.0001$

Carer

Male
$\chi^2 = 9.09$, $p = 0.01$

Younger
$F = 3.64$, $p = 0.03$

Non-spousal relationship
$\chi^2 = 13.43$, $P = 0.009$

Non co-resident
$\chi^2 = 18.51$, $p < 0.001$

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Cross-sectional effect of severity on quality of life: regression models

Self-reported quality of life (DEMQOL, self-report EQ5D, CASP)

- No significant effect of severity
- Accounted for less than 2% variance in the model

Proxy-reported quality of life (DEMQOL-Proxy, proxy-report EQ5D)

- Small effect of severity
- Accounted for between 4-6% variance in the model

Carer self-reported quality of life (EQ5D, SF-12 PHC, SF-12 MHC)

- No significant effect of dementia severity
- Accounted for less than 1% variance in the model

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Conclusions and Implications

- Dementia severity has little effect on quality of life of the person with dementia or the carer
- Dementia severity has little effect on quality of life of the person with dementia or the carer
- This may demonstrate the power of individual and familial adaptation to long term conditions including dementia
- Carer burden and the quality of life of the person with dementia may have a central role in the quality of life of the carer

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Thank you to the fieldwork team

- Sharne Berwald
- Elizabeth Bustard
- Ruth Habibi
- Claire Burgon
- Yvonne Feeney
- Laura Gallaher

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Change over time in quality of life and cost of care of persons with dementia – analysis of the MODEM cohort

Derek King, Sube Banerjee, Nicolas Farina, Bo Hu, Raphael Wittenberg, Amritpal Rehill, Klara Lorenz, Adelina Comas-Herrera, Ying Sheng Phang, Martin Knapp

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Aim of the study

Identify the factors associated with the changes over time in quality of life and societal costs associated with dementia

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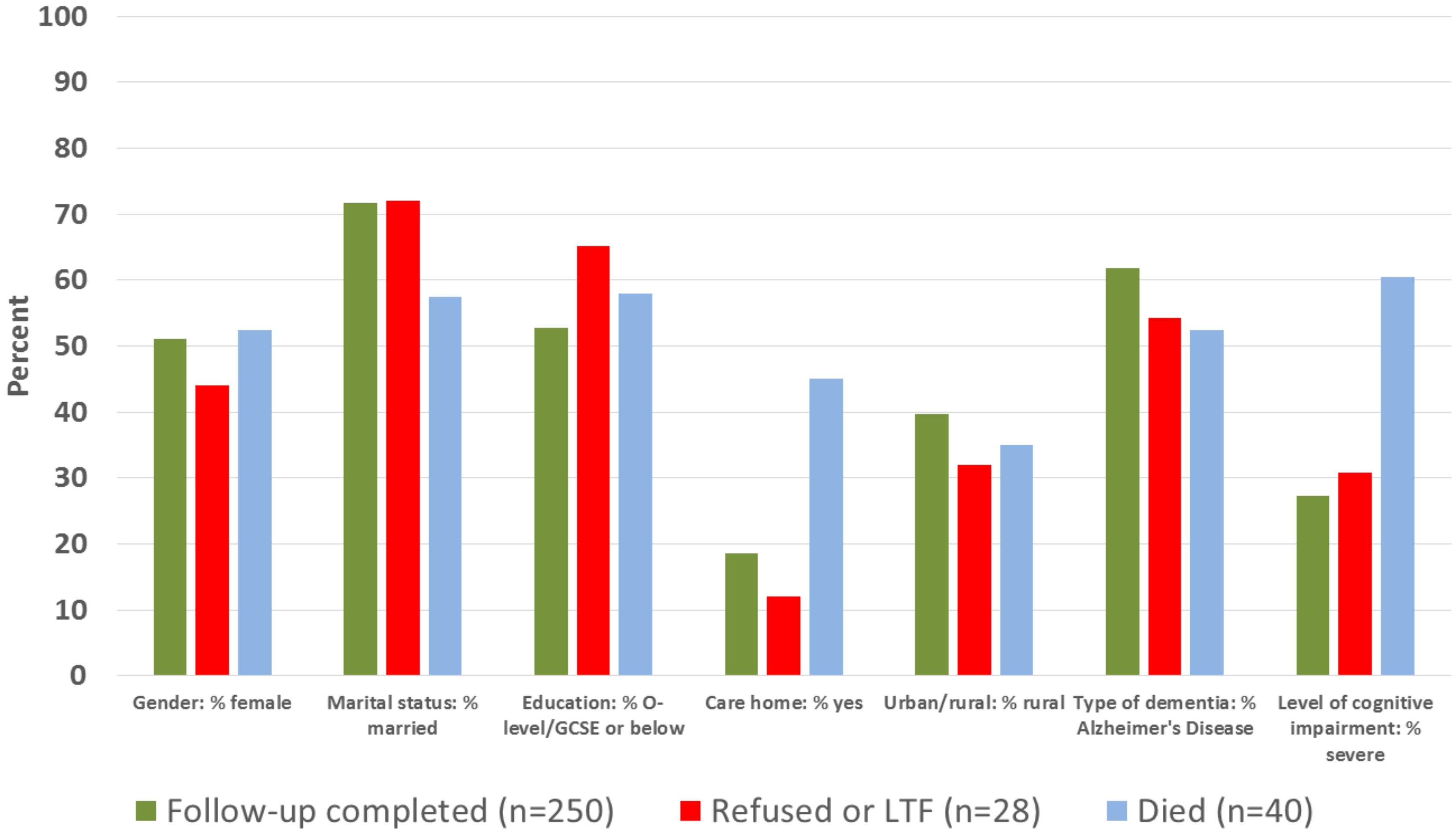
Outline

- MODEM sample at follow-up
- Change over time in quality of life
- Change over time in costs
- Summary and conclusions

Sample status at follow-up



Change over time – Cognitive impairment

Cognitive impairment at wave 1	Cognitive impairment at wave 2			
	Mild	Moderate	Severe	TOTAL
Mild	68	27	2	97
Moderate	9	36	26	71
Severe	0	0	50	50

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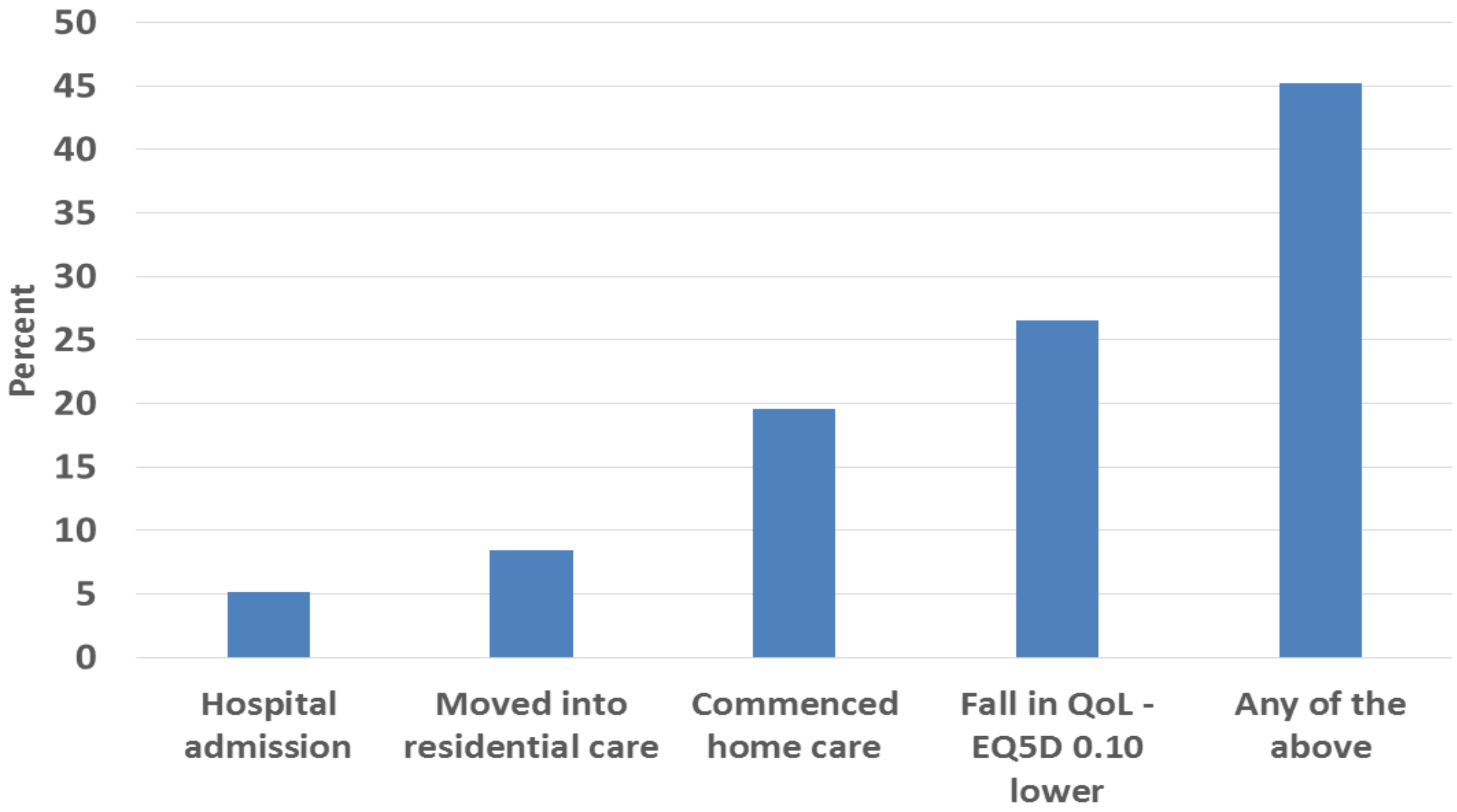
Change over time among completers, n=250



EQ-5D person with dementia, self assessed: Values at baseline by level of cognitive impairment at baseline and follow-up

Mean

		Follow-up		
		Mild (n=77)	Moderate (n=61)	Severe (n=39)
Baseline	Mild (n=107)	0.80	0.77	
	Moderate (n=77)	0.77	0.83	0.75
	Severe (n=23)			0.86

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EQ-5D proxy values at baseline: by level of cognitive impairment at baseline and follow-up

Mean

		Follow-up		
		Mild (n=73)	Moderate (n=62)	Severe (n=80)
Baseline	Mild (n=102)	0.67	0.60	
	Moderate (n=84)	0.67	0.53	0.53
	Severe (n=70)			0.34

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Factors associated with change over time in EQ-5D

	EQ-5D (n=151)	EQ-5D Proxy (n=260)
EQ-5D at baseline		
Age		
Gender – Male		
Education level		
Co-residence		
Setting - urban		
Relationship of carer		
Carer burden (Zarit Burden score) ↓		
Carer's GHQ score (minor psychiatric disorder measure) ↓		
Carer's SF-12 Mental Health Score ↑		
Alzheimer's disease		
Severity of cognitive impairment		
Level of disability		
Level of behavioural disturbance		
Increase in severity of cognitive impairment		
Increase in level of disability		
Increase in level of behavioural disturbance		

↑ - higher scores better; ↓-lower scores better.

Factors associated with change over time in EQ-5D

	EQ-5D (n=151)	EQ-5D Proxy (n=260)
EQ-5D at baseline	**EQ-5D at baseline**	**EQ-5D at baseline**
Age		**Age**
Gender – Male		
Education level		
Co-residence	**Co-residence**	
Setting - urban		
Relationship of carer		
Carer burden (Zarit Burden score) ↓	**Carer burden ↓**	
Carer's GHQ score (minor psychiatric disorder measure) ↓		
Carer's SF-12 Mental Health Score ↑		
Alzheimer's disease		
Severity of cognitive impairment		**Severity of cognitive impairment**
Level of disability		**Level of disability**
Level of behavioural disturbance		
Increase in severity of cognitive impairment		**Increase in severity of cognitive impairment**
Increase in level of disability		
Increase in level of behavioural disturbance		

↑ - higher scores better; ↓-lower score better.

Factors associated with change over time in EQ-5D

	EQ-5D (n=151)	**EQ-5D Proxy (n=260)**
EQ-5D at baseline	**EQ-5D at baseline**	**EQ-5D at baseline**
Age		**Age**
Gender – Male		
Education level		
Co-residence	**Co-residence**	
Setting - urban		
Relationship of carer		
Carer burden (Zarit Burden score) ↓	**Carer burden ↓**	
Carer's GHQ score (minor psychiatric disorder measure) ↓		
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Increase in level of behavioural disturbance		

↑ - higher scores better; ↓-lower score better.

Co-residence

Carer co-resident	-
Carer not co-resident	-0.13 (-0.27, 0.0)

Carer burden – 10 unit decrease in Zarit-Burden score: 0.03 (0.0, 0.05)

Severity

Mild	-
Moderate	-0.07 (-0.16, 0.02)
Severe	-0.29 (-0.41, -0.17)

Increase in severity -0.18 (-0.28, -0.09)

Disability

None	-
Need help with 1 or more IADLs	0.0 (-0.12, 0.12)
Difficulty with 1 ADL	-0.06 (-0.17, 0.04)
Difficulty with 2 or more ADLs	-0.14 (-0.27, -0.02)

Factors associated with change over time in DEMQOL

	DEMQOL (28-112) ↑ (n=151)	DEMQOL Proxy (31-124) ↑ (n=260)
DEMQOL at baseline		
Age		
Gender – Male		
Education level		
Co-residence		
Setting - urban		
Relationship of carer		
Carer burden (Zarit Burden score) ↓		
Carer's GHQ score (minor psychiatric disorder measure) ↓		
Carer's SF-12 Mental Health Score ↑		
Alzheimer's disease		
Severity of cognitive impairment		
Level of disability		
Level of behavioural disturbance		
Increase in severity of cognitive impairment		
Increase in level of disability		
Increase in level of behavioural disturbance		

↑ - higher scores better; ↓-lower scores better.

Factors associated with change over time in DEMQOL

	DEMQOL (28-112) ↑ (n=151)	DEMQOL Proxy (31-124) ↑ (n=260)
DEMQOL at baseline	**DEMQOL at baseline**	**DEMQOL at baseline**
Age		
Gender – Male		
Education level		
Co-residence		
Setting - urban		
Relationship of carer		
Carer burden (Zarit Burden score) ↓		
Carer's GHQ score (minor psychiatric disorder measure) ↓		
Carer's SF-12 Mental Health Score ↑		
Alzheimer's disease		**Alzheimer's disease**
Severity of cognitive impairment		
Level of disability		
Level of behavioural disturbance		
Increase in severity of cognitive impairment		
Increase in level of disability		
Increase in level of behavioural disturbance		**Increase in level of behavioural disturbance**

↑ - higher scores better; ↓-lower scores better.

Factors associated with change over time in DEMQOL

	DEMQOL (28-112) ↑ (n=151)	DEMQOL Proxy (31-124) ↑ (n=260)
DEMQOL at baseline	**DEMQOL at baseline**	**DEMQOL at baseline**
Age		
Gender – Male		
Education level		
Co-residence		
Setting - urban		
Relationship of carer		
Carer burden (Zarit Burden score) ↓		
Carer's GHQ score (minor psychiatric disorder measure) ↓		
Carer's SF-12 Mental Health Score ↑		
Alzheimer's disease		**Alzheimer's disease**
Severity of cognitive impairment		
Level of disability		
Level of behavioural disturbance		
Increase in severity of cognitive impairment		
Increase in level of disability		
Increase in level of behavioural disturbance		**Increase in level of behavioural disturbance**

Type of dementia
Other -
Alzheimer's disease 3.1 (0.7, 5.4)

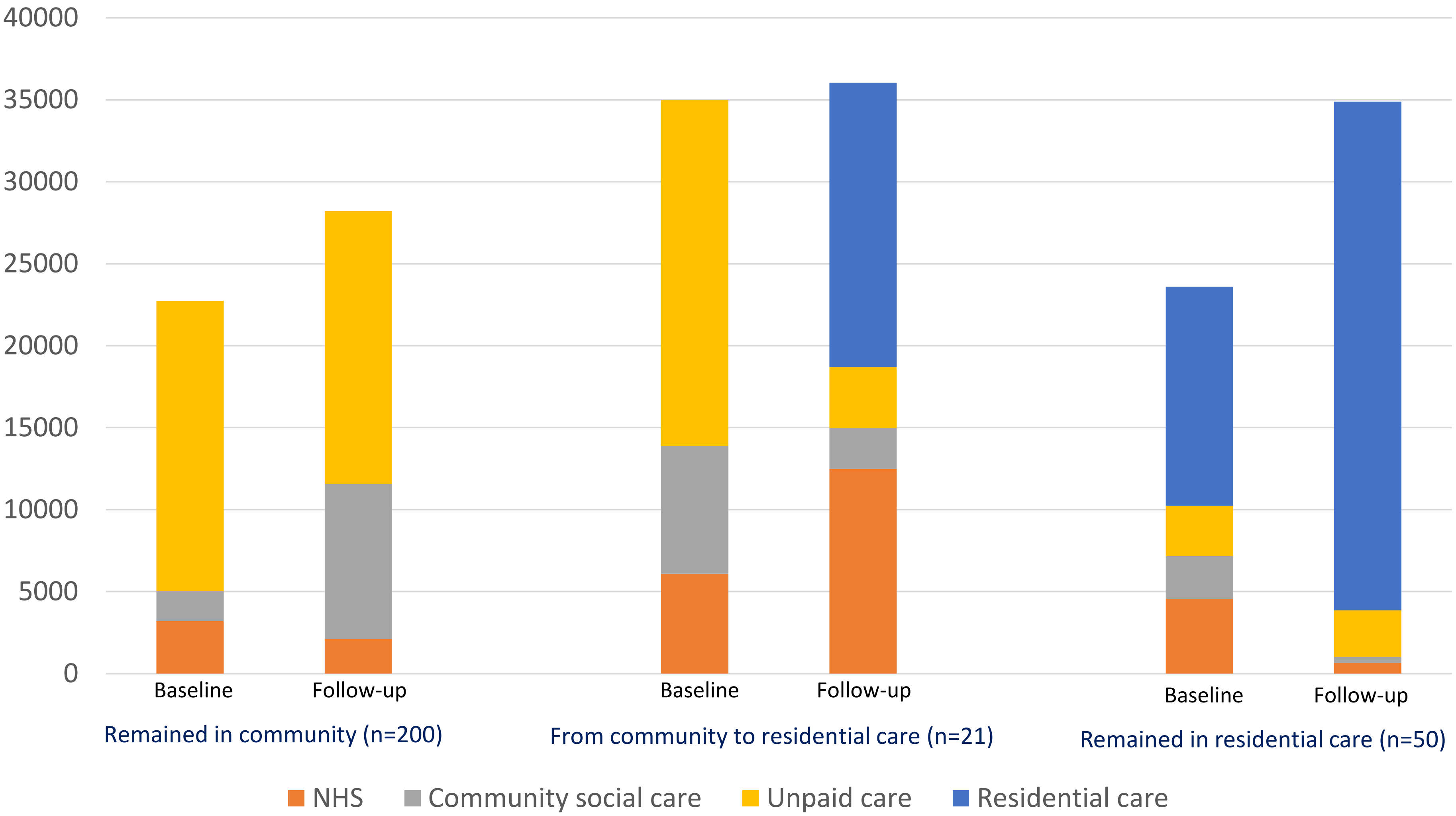
Increase in behavioural disturbance?
No -
Yes -4.3 (-6.6, -2.1)

↑ - higher scores better; ↓-lower scores better.

DEMQOL, DEMQOL proxy – Factors associated with change over time

	DEMQOL	DEMQOL proxy
Poorer quality of life… compared to improvement	Main carer not spouse or child	Alzheimer’s disease
	Lower behavioural disturbance at baseline	More behavioural disturbance over time
The same quality of life… compared to improvement	Older age	Carer burden
	Main carer not spouse or child	Alzheimer’s disease
	Low level of disability	

Average annual cost per person - by type of cost and care setting (*excludes deaths)



Estimates from the MODEM cohort

Summary and conclusions

- Greater carer burden and not living with main carer associated with lower EQ-5D values as rated by person with dementia
- Level of cognitive impairment in dementia and change in level of cognitive impairment negatively associated with change in EQ-5D proxy values

- Compared to those with clinically significant improvement in DEMQOL, those who declined significantly more likely to have reported behavioural disturbance at baseline
- Increase in behavioural disturbance strongly associated with reduction in DEMQOL-proxy scores over one year follow-up

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Summary and conclusions (2)

- Changes in costs vary over a one year period but are also substantially influenced by changes in setting
- Studies with a longer follow-up period may be required to observe the impact of transitions in level of cognitive impairment over time in dementia

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Mapping the Dementia Care Pathway in England

Adelina Comas-Herrera, Klara Lorenz, Amritpal Rehill, Jackie Damant, Derek King, Bo Hu, Raphael Wittenberg, Martin Knapp

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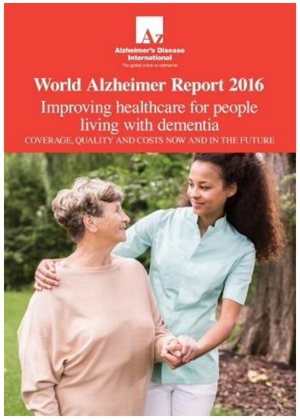
What is a dementia care pathway?

A way to summarise the stages of care experienced by people with dementia and their carers

Why is it a useful concept?

“a structured and organised approach to the planning, resourcing and delivery of continuing care”



Alzheimer's Disease International

World Alzheimer Report 2016

Improving healthcare for people living with dementia

COVERAGE, QUALITY AND COSTS NOW AND IN THE FUTURE

www.alz.co.uk/worldreport2016

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Why do we consider the Dementia Care Pathway in MODEM?

- Modelling of the costs and impacts of increases in the numbers of people accessing cost-effective dementia interventions
- Raised two questions:
  - How many people are accessing those interventions today?
  - How will more people access those interventions, will that depend on access to “previous” services?

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Aims of the MODEM Dementia Care Pathway

- To understand how to improve access to services: are there bottle necks or discontinuities that result in people “falling through the cracks”?

- To simulate what would be the impact of making dementia services and interventions available to more people

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What we set out to do

- To map the health and social care services available to people with dementia and carers, ensuring we capture the “sequence” of services and interdependencies (*phase I*)

- To build a model to simulate how a cohort of people move through the system, from first symptoms and service contacts to the end of life (*phase II*?)

A BIG challenge: DATA

- No nationally representative, longitudinal dataset where people with dementia and their carers can be identified and are followed up regularly

- Health and social care records: it takes a long time to obtain access/ issues of matching records… but an option for the future

Methods

- Wide consultation on pathway elements – with people with dementia, carers, clinical staff, researchers, national clinical director etc, using graphical representations

- Gathering data on the numbers of people accessing each "stage of care" from all available sources

5 pathway stages:

1. Pre-diagnosis to referral

- Early symptom identification & first service encounters, including GP assessments and hospital-based screening

2. Diagnostic process

- From point of referral to diagnostic services (memory clinic, other specialists), including diagnostic disclosure

3. Post-diagnostic support

- Includes care, treatment and support during first year after diagnosis

4. Ongoing care

- Medication reviews
- Addressing behavioural and other symptoms and co-morbidities
- Formal social care support, voluntary sector support

5. End of life care

- Assumed to be last year of life with dementia

Dementia Care Pathway MAP or MODEL?

We have a **map** of (nearly) the full Dementia Care Pathway

And

A model that simulates the dementia diagnostic pathway

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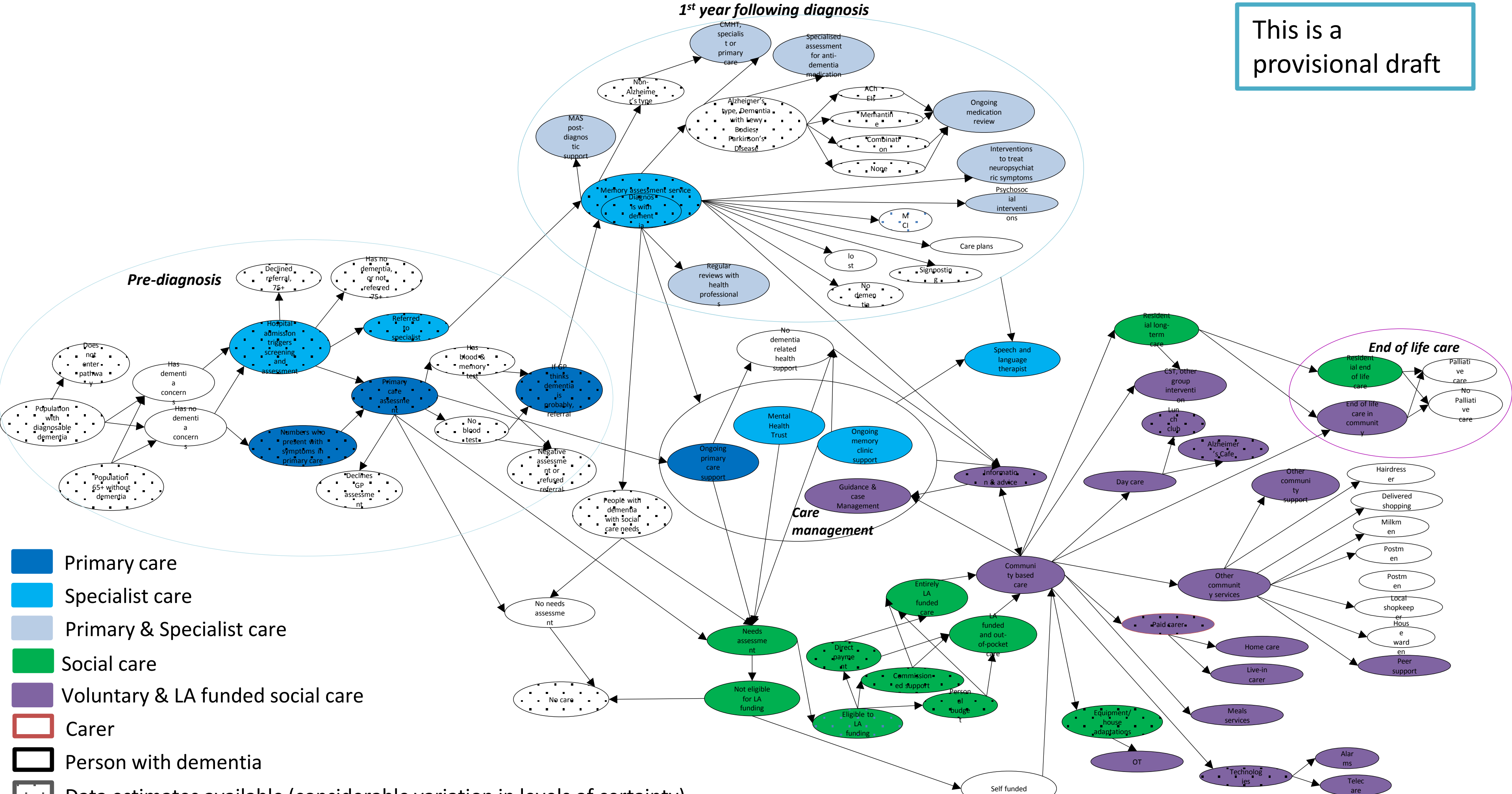
THE DEMENTIA CARE PATHWAY IN ENGLAND

The Pathway for people with Dementia in England

This is a provisional draft



🟦 Primary care

🟦 Specialist care

🟦 Primary & Specialist care

🟩 Social care

🟪 Voluntary & LA funded social care

▭ Carer

▭ Person with dementia

⬚ Data estimates available (considerable variation in levels of certainty)

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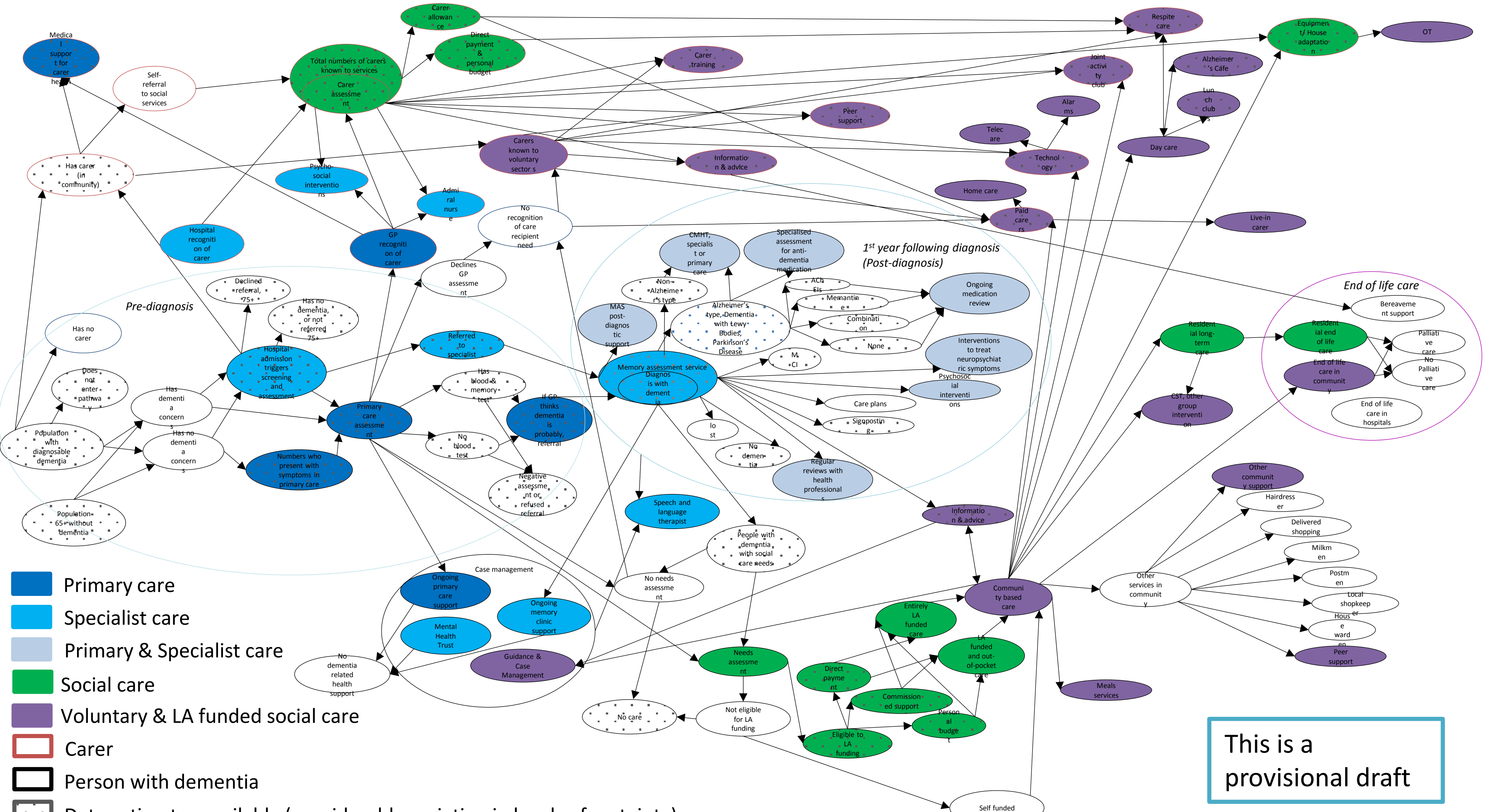
AND NOW WE INCLUDE UNPAID (MOSTLY FAMILY) CARERS:

The Pathway for people with Dementia and their carers in England



Medical support for carer health
Self-referral to social services
Total numbers of carers known to services
Carer assessment
Carer allowance
Direct payment & personal budget
Carer training
Peer support
Carers known to voluntary sectors
Information & advice
Respite care
Joint activity club
Alarms
Telecare
Technology
Home care
Paid carers
Live-in carer
Day care
Alzheimer's Cafe
Lunch clubs
Equipment/ House adaptation
OT
Has carer (in community)
Psycho-social interventions
Admiral nurse
Hospital recognition of carer
GP recognition of carer
No recognition of care recipient need
Declines GP assessment

Pre-diagnosis

Has no carer
Declined referral, 75+
Has no dementia, or not referred 75+
Does not enter pathway
Hospital admission triggers screening and assessment
Referred to specialist
Has dementia a concerns
Has no dementia a concerns
Population with diagnosable dementia
Population 65+ without dementia
Numbers who present with symptoms in primary care
Primary care assessment
Has blood & memory test
No blood test
If GP thinks dementia is probably, referral
Negative assessment or refused referral

1st year following diagnosis (Post-diagnosis)

CMHT, specialist or primary care
Specialised assessment for anti-dementia medication
Non-Alzheimer's type
MAS post-diagnostic support
Alzheimer's type, Dementia with Lewy Bodies, Parkinson's Disease
AChEIs
Memantine
Combination
None
Ongoing medication review
Interventions to treat neuropsychiatric symptoms
Psychosocial interventions
Memory assessment service
Diagnosis is with dementia
MCI
Care plans
Signposting
lost
No dementia
Regular reviews with health professionals
Speech and language therapist
People with dementia with social care needs
Information & advice

End of life care

Bereavement support
Residential long-term care
Residential end of life care
End of life care in community
Palliative care
No Palliative care
End of life care in hospitals
CST, other group intervention
Other community support
Hairdresser
Delivered shopping
Milkmen
Postmen
Local shopkeeper
House warden
Peer support
Other services in community
Community based care
Meals services
Case management
Ongoing primary care support
Ongoing memory clinic support
Mental Health Trust
Guidance & Case Management
No dementia related health support
No needs assessment
Needs assessment
Not eligible for LA funding
No care
Self funded
Entirely LA funded care
LA funded and out-of-pocket care
Direct payment
Commissioned support
Personal budget
Eligible to LA funding

🟦 Primary care
🟦 Specialist care
🟦 Primary & Specialist care
🟩 Social care
🟪 Voluntary & LA funded social care
▭ Carer
▭ Person with dementia
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The Pathway for people with Dementia and their carers in England

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1st year following diagnosis (Post-diagnosis)

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Good luck finding your way!

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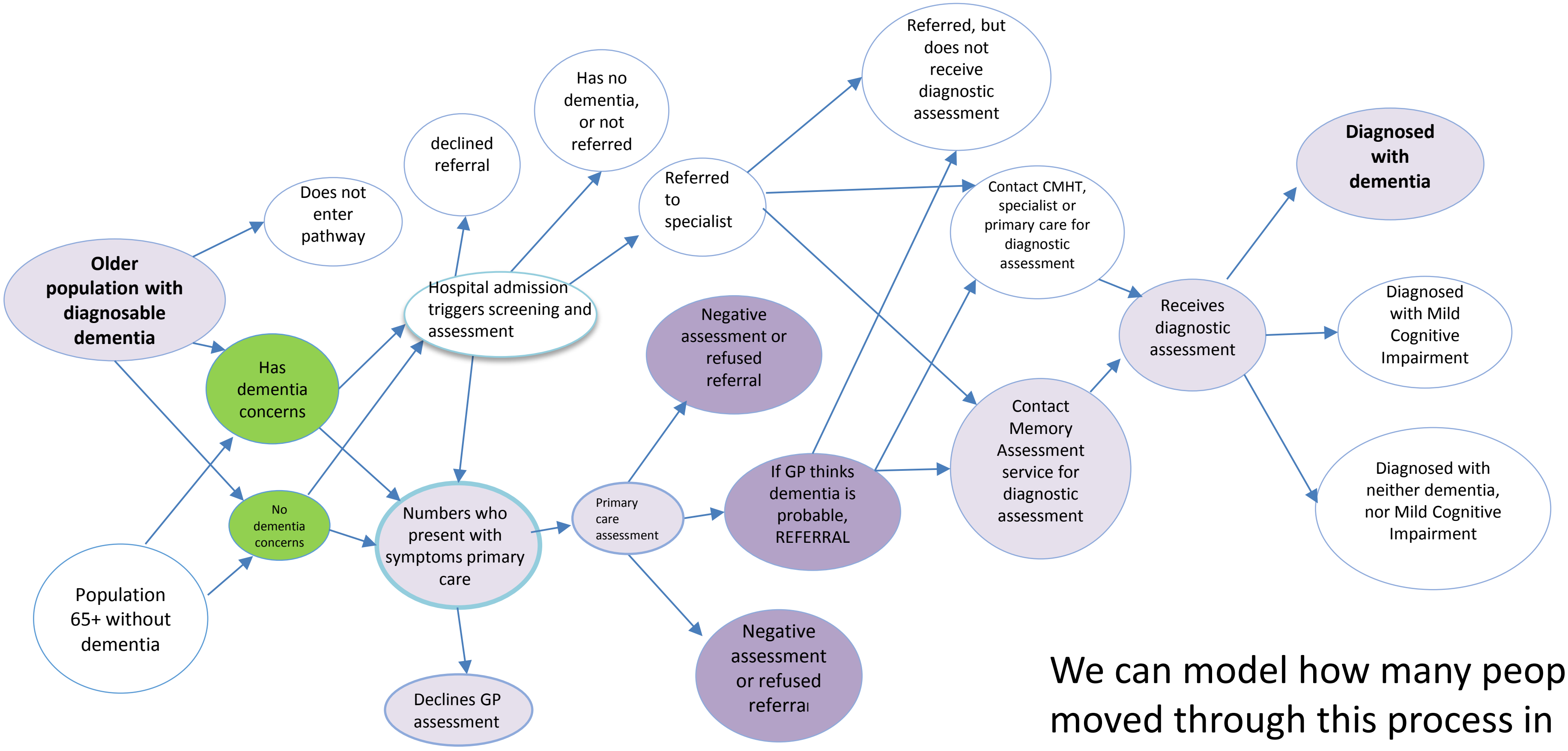
A SIMULATION MODEL OF THE DEMENTIA DIAGNOSTIC PROCESS

Our MODEM Dementia diagnostic process simulation model so far:



We can model how many people moved through this process in 2015, how much it costed and how long it took. MORE SOON!

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And how is this work useful?

COMPARING POLICY ASPIRATIONS WITH SERVICE ACCESS REALITIES

UK dementia policy has been lacking in ambition:

Dementia

UK will be most dementia-friendly country, says Jeremy Hunt

Health secretary says by 2020, under new government plans, dementia research, care and diagnosis will be best in world

Press Association

Sun 6 Mar 2016
00.01 GMT

1935

This article is over 2 years old

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Some of the big numbers of dementia in England (2015 estimates)

Numbers of older people living with dementia	**650,799**
Numbers with Alzheimer's Disease	403,495
Numbers of older people with dementia who have a diagnostic	412,722
Numbers taking anti-dementia medication	146,245
Numbers with anti-psychotic prescriptions	49,048
Numbers of people with dementia and care needs	586,517
Numbers of people with dementia and care needs living in the community	335,707
Numbers of carers of people with dementia	258,638
Number of carers of people with dementia who provide 10 or more hours of care	223,362
Numbers of people with dementia, care needs and no care (paid or unpaid)	68,880
Numbers of people with dementia in the community who saw a GP in last 3 months	229,157

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POLICY ASPIRATIONS	SERVICE REALITIES
Diagnostic:	
Achieve and maintain **diagnosis rate** of at least 2/3 (*66%, NHS benchmark*)	
Post-diagnostic support:	
People diagnosed have an up-to-date care plan (*NICE & NHS "diagnosing well"*)	
People diagnosed meet a named coordinator of care (*NICE & NHS "diagnosing well"*)	
Consider group Cognitive Stimulation Therapy (CST) for people with mild to moderate dementia (*NICE*)	
Personal care	
"Improved… personal support services… accessible to those who live alone or with carers and people who pay for their care privately" *(National Dementia Strategy)*	

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POLICY ASPIRATIONS	**SERVICE REALITIES**
Diagnostic:	
Achieve and maintain **diagnosis rate** of at least 2/3 (*66%, NHS benchmark*)	**67.8%** (August 2018) but local variation (58 to 71%)
Post-diagnostic support:	
People diagnosed have an up-to-date care plan (*NICE & NHS "diagnosing well"*)	*Estimated: **65%** of people with diagnosis have a care plan/review in GP records*
People diagnosed meet a named coordinator of care (*NICE & NHS "diagnosing well"*)	No data
Consider group Cognitive Stimulation Therapy (CST) for people with mild to moderate dementia (*NICE*)	*Estimated: **11%** of people newly diagnosed in 2015 took part in CST*
Personal care	
"Improved… personal support services… accessible to those who live alone or with carers and people who pay for their care privately" *(National Dementia Strategy)*	*Estimated: **20%** people with dementia with personal care needs living in the community receive **no care**, another **54%** receive **only unpaid care***

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POLICY ASPIRATIONS (contd.)	SERVICE REALITIES (contd.)
Support for carers	
Carers providing regular & substantial care have a right to a carers assessment (NICE & Care Act 2014)	
Offer carers a psychoeducation & skills training intervention (NICE)	
Respite care!	

POLICY ASPIRATIONS (contd.)	**SERVICE REALITIES (contd.)**
Support for carers	
Carers providing regular & substantial care have a right to a carers assessment (NICE & Care Act 2014)	*Estimated: 39% of carers of people with dementia living in the community had a carer's assessment, (45% among carers providing 10 + hours of care per week) (MODEM dataset)*
Offer carers a psychoeducation & skills training intervention (NICE)	*Estimates:* *Support groups:* ***22%*** *Education groups:* ***8%*** *Carer training:* ***7%*** *Alzheimer café:* ***7%*** *Counselling:* ***5%*** *(MODEM dataset)*
Respite care!	*Still trying to make sense of the data!*

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Respite care!	*Still trying to make sense of the data!*

Conclusions

- The care pathway for people living with dementia (and their carers) is hugely complex
- There is a clear pathway until the point of diagnostic, after that, no “system” & no monitoring.
- Only policy aspiration that is clearly achieved is diagnostic rate (which carried financial incentives).
- Care ambitions may take a bit longer to achieve!

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MODEM Final Conference,
15 November 2018

Projections of care needs and the contribution of dementia

Carol Jagger, Andrew Kingston, Heather Booth, Louise Robinson and the MODEM team

#Modellingdementia @MODEMProject

Population Ageing & Care Simulation (PACSim)

PACSim is a dynamic microsimulation model which

- Simulates future health conditions, dependency and survival of 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

PACSim data

Age 35+ Years

Understanding Society
THE UK HOUSEHOLD LONGITUDINAL STUDY
+ ELSA English Longitudinal Study of Ageing + CFAS II
Cognitive Function & Ageing Study

Survival
ONS 2014 population projections

Sociodemographic factors
Age, sex, education, marital status, occupation

Lifestyle factors
Smoking, physical activity, BMI

Morbidity
CHD, hypertension, diabetes, arthritis, stroke, respiratory disease, cancer, depression, **dementia**, cognitive impairment, visual impairment, hearing impairment

Dependency
High (requires 24 hr care)
Medium (requires care daily)
Low (requires care < daily)
Independent

Based on help required with (I)ADLs, cognitive impairment and incontinence

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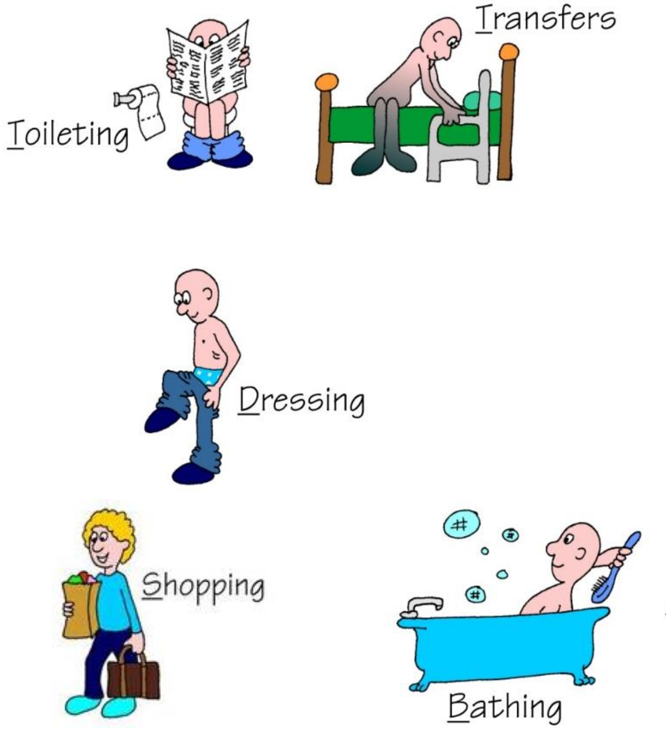
Measuring dependency

- Interval of need (Isaacs and Neville, 1975):
  - **High (requires 24-hour care)**
    - bedbound or chairbound, or unable to get to or use the toilet without help, or need help feeding, or be often incontinent and need help dressing, or have severe cognitive impairment (MMSE < 10)
  - **Medium (requires help at regular times daily)**
    - need help preparing a meal, or dressing
  - **Low (requires help less than daily)**
    - need help to wash all over or bath, or cut toenails, or shop, or do light or heavy housework
  - **Independent**



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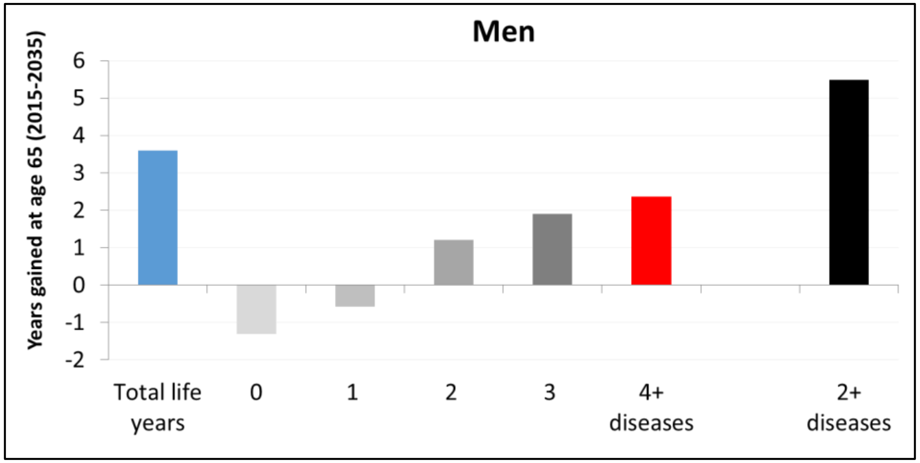
PACSim: increase in multi-morbidity 2015 to 2035

Between 2015 and 2035:

- Numbers of older people with multi-morbidity (2+ diseases) will increase by 86% (from 5.3m to 9.8m)
- Numbers with 4+ diseases (complex multi-morbidity) will increase by 158% (from 1.0m to 2.5m)

Gain in years spent with multi-morbidity (2+ diseases) will exceed gains in life expectancy



Expansion of morbidity

Kingston A, Robinson L, Booth H, Knapp M, Jagger C. *Age and Ageing* 2018; 47: 374–380

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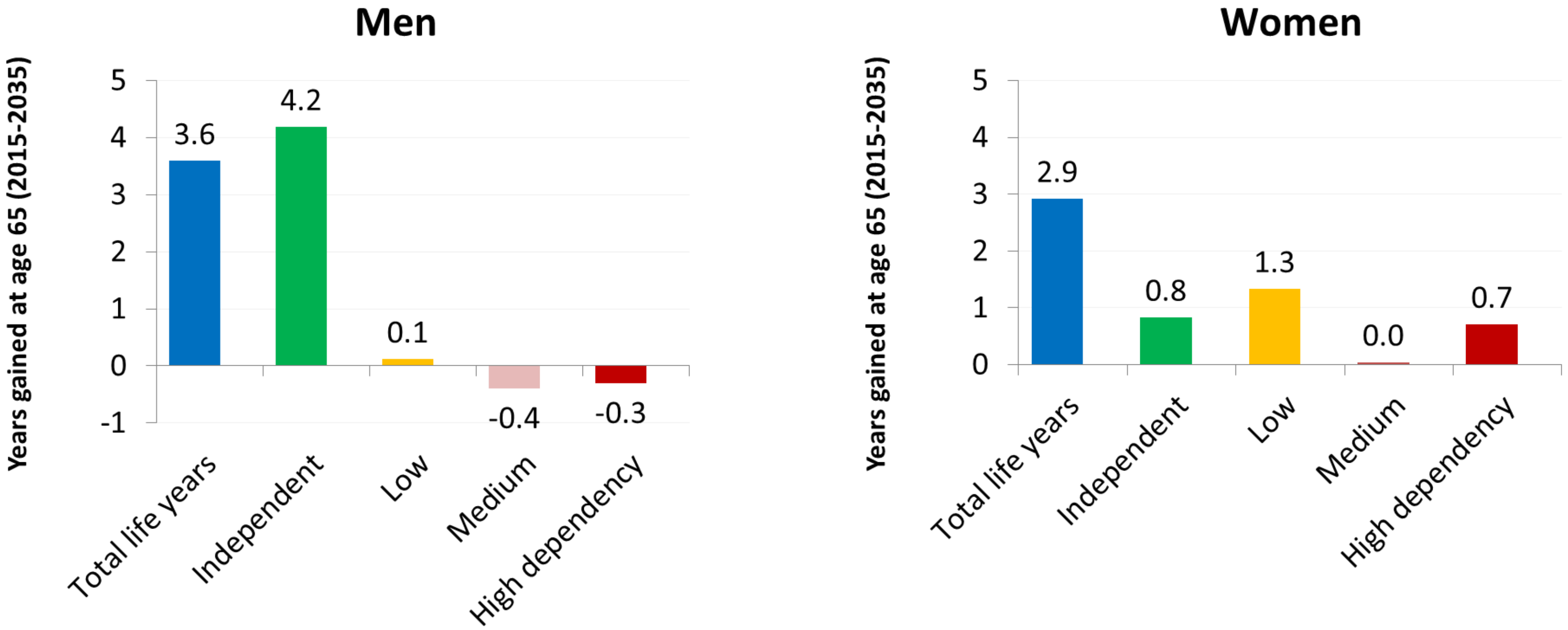
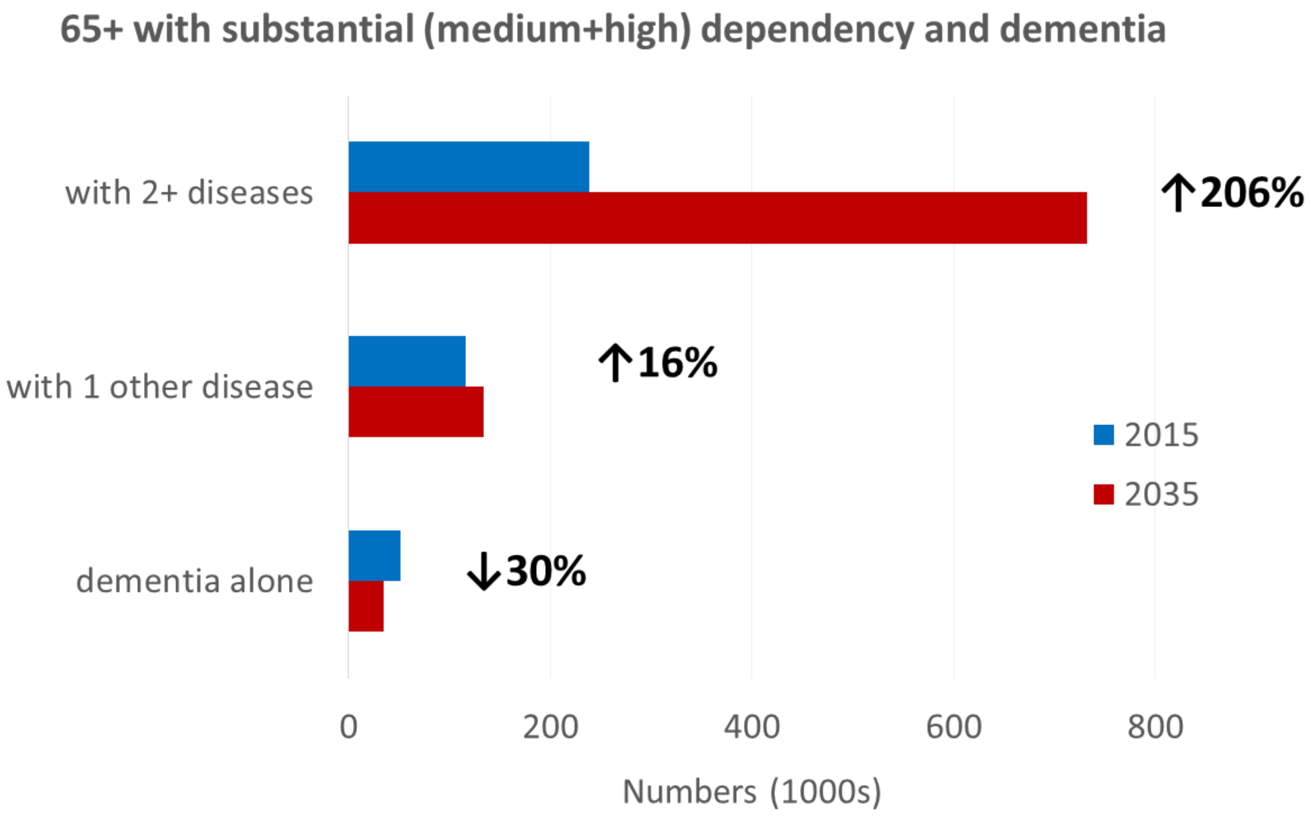
PACSim: Years needing care - change 2015 to 2035



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

PACSim: greater contribution of comorbidity



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

Benefits of PACSim

- Base population (and transitions) of real individuals
  - 3 large, nationally representative longitudinal studies in 2011
  - aged 35+ to enable projections for 65+ to 2041
- Individual diseases as well as multi-morbidity
  - Comorbid conditions alongside dementia
- Health behaviours for modelling of PH interventions
- Incorporates risk factor profiles of those ageing into older population
- Life and health expectancies for potential of compression of morbidity

PACSim in the news

Age and Ageing 2018; **47:** 374–380
doi: 10.1093/ageing/afx201
Published electronically 24 January 2018

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

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**

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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

Health

Number of Britons living with chronic illnesses set to rise

Life expectancy set to increase but sedentary lifestyles will lead to more chronic illnesses, says report

▲ The number of people aged above 85 is set to double from 1.3million in the next 20 years in the UK. Photograph: Kirsty O'Connor/PA

NEWS

Health

Numbers of elderly in 24-hour care set to double by 2035

By Laurel Ives
BBC Health

31 August 2018

DAILY NEWSPAPER OF THE YEAR

THE TIMES

Wednesday January 24 2018 | thetimes.co.uk | No 72440

Only £1 to subscribers £1.60

Now the Northern Irish want a bridge built from Scotland

Patrick Maguire

Continued on page 8, col 1

Fighting it out Dunkirk is in contention for eight Oscars after nominations were revealed. They include the best showing for British actors in 25 years. Pages 12-13

Top school bans pupils from having relationships

Nicola Woolcock
Education Correspondent

Britain's strictest head teacher, page 5

Lazy lifestyles to cause surge in serious illness

Middle-aged warned millions of older people will have four diseases in 20 years

Chris Smyth Health Editor

Continued on page 6, col 4

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MODEM Final Conference,
15 November 2018

Projected costs of care for people with dementia

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

Costing dementia: data and methods

- ONS population estimates for England
- Prevalence and incidence of dementia from CFASII, PACSim analysis and estimate for early onset
- NHS Digital data on local authority funded care
- Analyses of CFASII data on receipt of unpaid care and care services and relationship between them
- MODEM cohort study and NHS Digital data on weekly costs of unpaid care and care services

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Cost of dementia

- Around 690,000 people live with dementia in England, of whom 650,000 are aged 65 and over
- Total annual cost of dementia in England is estimated to be £24.2 billion, of which £10.1 billion (42%) is attributable to unpaid care
- Social care costs (£10.2 billion) are three times larger than healthcare costs (£3.8 billion)
- £6.2 billion of the total social care costs (60%) are met by users themselves and their families

Projections: data and assumptions

- ONS 2014-based principal population projections
- PACSim findings on trends in cognitive impairment and dependency by age, gender and education
- 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 numbers of older people living with dementia

- The number of older people with dementia in England is projected to rise from 650,000 in 2015 to 1,350,000 in 2040 (108% increase)
- The number with mild dementia is projected to rise by 52%, with moderate dementia by 16% and with severe dementia by 199%
- These projections are based on the outputs of the microsimulation modelling linked to ONS principal population projections

Care users living with dementia

- The number of older people with dementia receiving unpaid care is projected to rise from 260,000 in 2015 to 475,000 in 2040 (by 83%)
- The number receiving formal community-based services is projected to rise from 85,000 in 2015 to 190,000 in 2040 (by 120%)
- The number receiving residential care is projected to rise from 250,000 in 2015 to 665,000 in 2040 (by 165%)

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Projected costs of dementia care

- The cost of health care for older people with dementia is projected to rise from £3.5bn in 2015 to £10.3bn in 2040 (by 194%) at 2015 prices
- The cost of social care is projected to rise from £9.8bn in 2015 to £39.5bn in 2040 (by 303%)
- The cost of unpaid care is projected to rise from £9.5bn in 2015 to £29.8bn in 2040 (by 213%)
- The total cost is projected to rise from £23.0bn in 2015 to £80.1bn in 2040 (by 249%)

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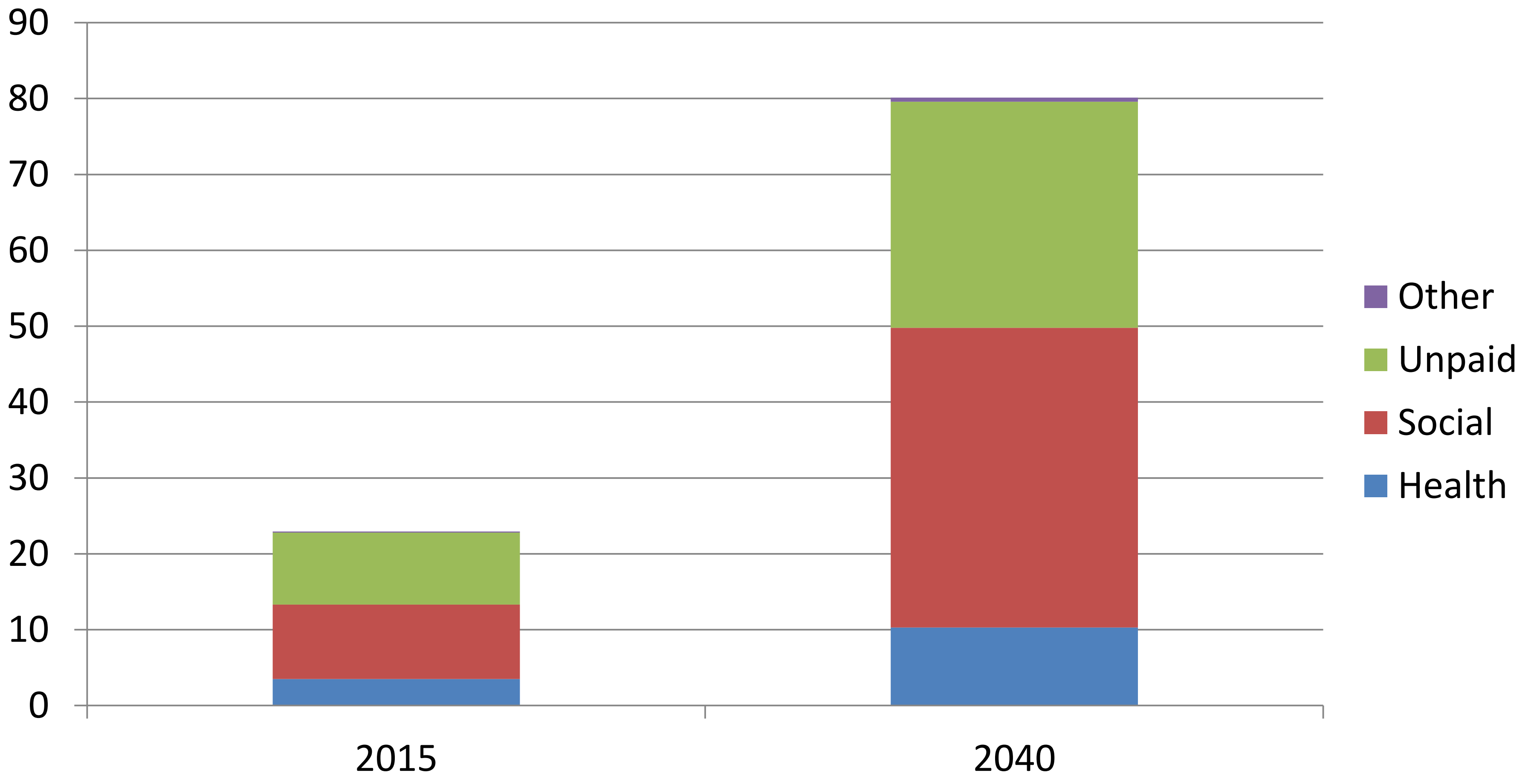
Projected costs of dementia care

(#billion at 2015 prices)



Conclusions

- The cost of dementia in England is around £24.2 billion, of which £23.0bn relates to older people
- The number of older people living with dementia is projected to more than double by 2040
- The total cost is projected to rise by almost 250%, from £23.0bn in 2015 to £80.1bn in 2040
- These findings are sensitive to assumptions including that the supply of carers will rise in line with demand

MODEM Final Conference,
15 November 2018

Scaling up evidence-based interventions – to 2040

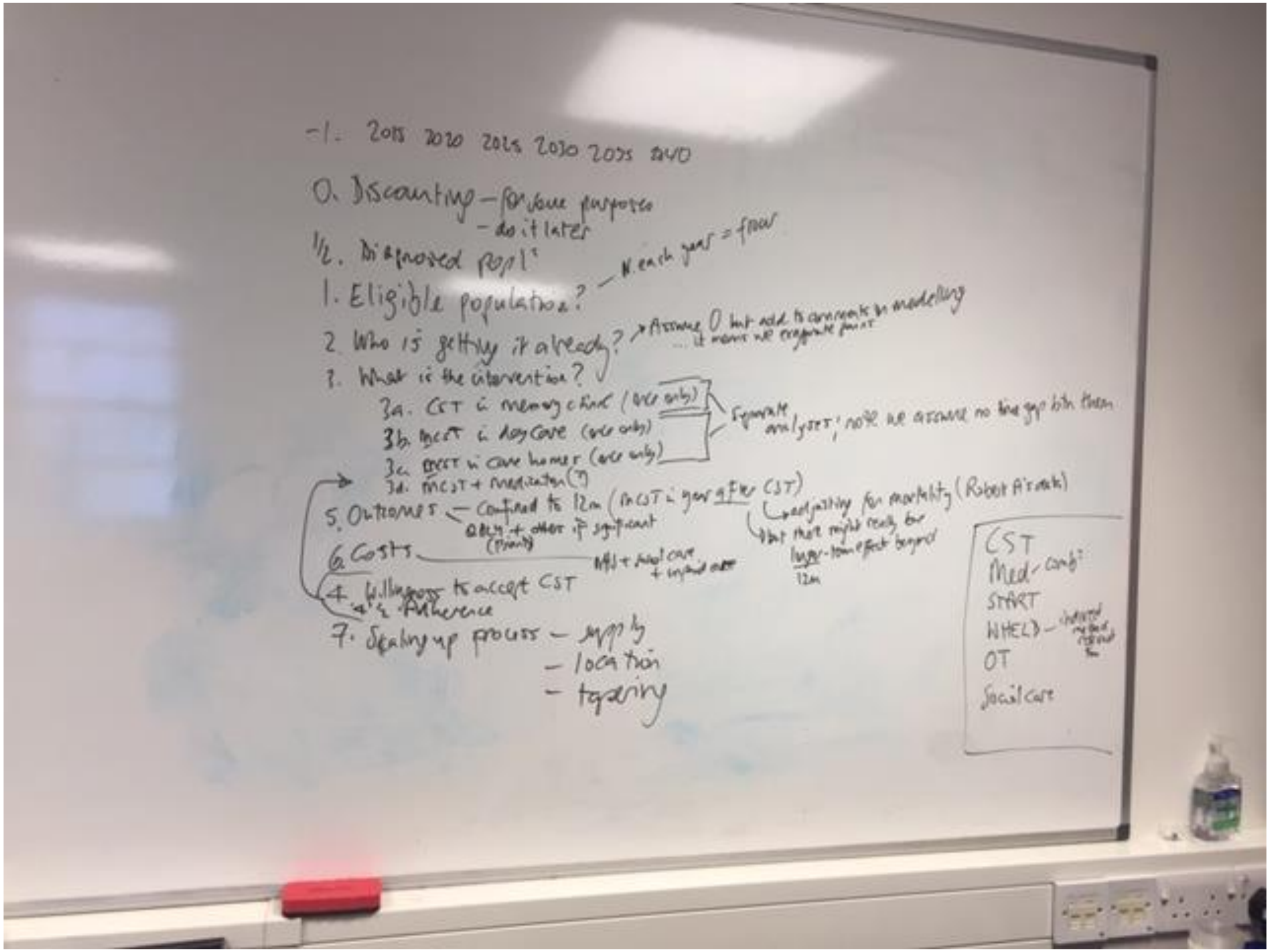
Martin Knapp, Raphael Wittenberg, Annette Bauer, A-La Park, Klara Lorenz, Adelina Comas-Herrera, Audrey Wessel, Carol Jagger

#Modellingdementia @MODEMProject

Scaling-up: purpose

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

Methods



-1. 2015 2020 2025 2030 2035 2040

0. Discounting – for value purposes
 – do it later

1/2. Diagnosed popl^n

1. Eligible population? – N. each year = flow

2. Who is getting it already? → Assume 0 but add to comments in modelling
 … it means we exaggerate point

3. What is the intervention?
 - 3a. CST in memory clinic (once only)
 - 3b. MCST in day care (once only)
 - 3c. MCST in care homes (once only)
 - 3d. MCST + medication (?)

Separate analyses; note we assume no time gap b/n them

5. Outcomes – confined to 12m (MCST in year after CST)
 QALY + others if significant (primary)
 – adjusting for mortality (Robert A's mark)
 – but there might really be longer-term effect beyond 12m

6. Costs – NHS + social care + unpaid care

4. Willingness to accept CST
 4½ Adherence

7. Scaling up process – supply
 – location
 – tapering

CST
Med-comb?
START
WHELD – [illegible]
OT
Social care

Methods: the *readable* version

1. Selected ***years*** (2015, 2020, 2025, 2030, 2035, 2040)
2. ***Diagnosed*** population
3. ***Eligible*** population (dementia severity; disability, using certain facilities etc.)
4. People ***getting it already*** (2015)
5. Specify the ***intervention***
6. Willingness to ***accept; adherence***
7. ***Outcomes*** – dimensions, duration
8. ***Costs*** – categories, duration
9. ***Scaling up*** process over time

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Principles (at this stage)

A. Interventions must have ***robust evidence on effectiveness***; ideally also on cost-effectiveness

B. ***Projections*** from PACSim and macrosimulation models

C. ***Eligibility***, ***willingness*** to accept etc. from literature & interviews with UK experts

D. ***Outcome data*** from the best UK trials

E. ***Cost data*** from best UK trials; otherwise from MODEM

F. ***Cost differences*** scaled-up even if not statistically significant

G. No ***discounting*** across future years used today

H. ***Sensitivity*** analyses later

Candidate interventions

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

- Cognitive stimulation therapy (CST)
- Anti-dementia medicatios (combination therapy)
- Carer support (START)
- Person-centred care intervention in care homes (WHELD)*

*not shown today

CST: what is it?

Cognitive stimulation therapy - 14 sessions (twice-weekly) of structured 45-minute group therapy sessions. Range of activities to stimulate thinking, memory and connect with others, such as:

- discussing current news stories
- listening to music or singing
- playing word games
- doing a practical activity (e.g. baking)

For people with mild-to-moderate dementia. Relaxed, fun, create opportunities for people to learn, express views, work with others in sociable setting.

Maintenance programme of CST (MCST) – follow-on 24 weekly sessions following same structure & principles as CST

Spector et al (2006) *Making a Difference: An Evidence-Based Group Programme to Offer Cognitive Stimulation Therapy (CST) to People With Dementia*. London: Hawker Publications.

CST: effectiveness & cost-effectiveness

CST compared to usual care:

- ***Outcomes***: Improves memory and thinking skills; quality of life; proxy-reported language and willingness to join in conversations
- ***Health & social care costs*** slightly higher (not significant) for CST
- High probability that CST would be seen as ***cost-effective***

MCST compared to usual care:

- ***Outcomes***: Improves quality of life; no impact on cognition
- Anti-dementia medication + MCST improves cognition
- ***Health & social care costs*** slightly higher (not significantly)
- ***Cost-effectiveness*** depends on outcome; more C-E on proxy-rated QALYs
- Medication + MCST more ***cost-effective*** than medication alone; cost per QALY below NICE threshold

Spector et al *BJPsych* 2003; Knapp et al *BJPsych* 2006; Aguirre et al IJGP 20013 Orrell *IJGP* 2014

CST: scaling-up, 2015 to 2040

People with better cognition & QOL

- 37,000 in 2020
- 54,000 in 2040

Additional **QALYs**

- 2600 in 2020
- 2800 in 2040

Total costs (incl. carer)

- £106m in 2020
- £161m in 2040

Health & social care service costs

- £21m in 2020
- £32m in 2040

Cost per QALY

- £8,000 in 2020
- £11,000 in 2040

TENTATIVE RESULTS

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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.

Livingston et al *BMJ* 2013

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START: effectiveness & cost-effectiveness

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

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

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 <u>savings</u>

- £50m in 2020
- £105m in 2040

Over 24m:

- better outcomes
- lower costs

Continue to 72m?

TENTATIVE RESULTS

Combination pharmacotherapy: what is it?

NICE guidance (2018):

- ‘Acetylcholinesterase (AChE) inhibitors (donepezil, galantamine, rivastigmine) as monotherapies are recommended as options for managing mild to moderate Alzheimer's disease.’

Combine AChE with memantine?

- Mild-to-moderate stage – from US, French studies
- Moderate-to-severe – from DOMINO (not shown)

NICE 2018; Touchon et al *EJHE* 2014; Howard et al *NEJM* 2012; Knapp et al *IJGP* 2017

Comb. meds: effectiveness & cost-effectiveness

- US observational study (Lopez et al 2009) suggested AChE + memantine generates delays nursing home admission compared to AChE alone
- French study (Touchon et al 2014) modelled these results: costs and QALYs
- However, systematic review & meta-analysis (Molino et al 2013) did not find evidence of improvement with combination therapy

Lopez et al *JNNP* 2009; Touchon et al *EJHE* 2014; Molino et al *Sci World J* 2013

Comb. meds: scaling-up, 2015 to 2040

Eligible people with mild-moderate AD

- 131,000 in 2020
- 188,000 in 2040

Additional **QALYs**

- 10,800 in 2020
- 31,500 in 2040

Health & social care service <u>savings</u>

- £2.64bn in 2025
- £4.75bn in 2040

Total societal cost increase:

- £1.41bn in 2025
- £2.76bn in 2040

High costs to carers

TENTATIVE RESULTS: PLEASE DO NOT QUOTE

Can the future ‘dementia challenge’ be met with better treatment and care?

- Scaling up evidence-based interventions can improve ***cognition, health and quality of life*** …
- … sometimes also ***savings*** to health & social care systems
- … sometimes at ***higher (net) cost*** but in a way that is considered ***cost-effective*** (‘worth it’) by NICE
- … but sometimes savings in health & social care service costs are smaller than ***increases in cost of carer time***.
- Challenge? Can we ***recruit, train, retain enough staff*** to deliver these interventions?

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Rapid fire

#Modellingdementia @MODEMProject

MODEM Final Conference,
15 November 2018

Methods of calculating hours of care in MODEM

Amritpal Rehill, Adelina Comas-Herrera,
Derek King, Martin Knapp, Klara Lorenz

#Modellingdementia @MODEMProject

Why consider measurement of unpaid care hours?

- Unpaid care can have large impacts on outcomes for both people with dementia and carers.
- It's usually the largest cost component when included- for example, it accounted for 44% of the estimated total cost of dementia to the UK in 2013 (Prince & Knapp *et al.*[1])
- What is being measured can vary by method (e.g. care needed versus care supplied).

[1] Prince M, Knapp M, Guerchet M et al. (2014) *Dementia UK: Update*. London: Alzheimer's Society

Methods used to estimate hours of care in MODEM

Method	Estimated average hours per week found in cohort
1. Ask all carers for total number of care hours per day	71
2. Ask co-resident and extra-resident carers for total hours in different ways	90
3. "Bottom-up" estimation of time spent on tasks	105

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Further analyses

- Using regression analyses, we looked at what factors are associated with differences in care hours reported using different methods.

- Factors such as sleep disruption, severity of dementia and score on the neuro-psychiatric inventory were associated in one estimate of care hours being higher or lower than another.

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Economic evaluation & dementia research: state of the art

David McDaid, A-La Park and
Adelina Comas-Herrera

Why include a mapping review?

Can cover a wide range of literature systematically

No focus on one specific intervention– but on methods

Aim is to get an broad, overview of state of literature & trends in research and methods used

Help identify where work concentrated / and gaps

Identify future expected trends through published protocols

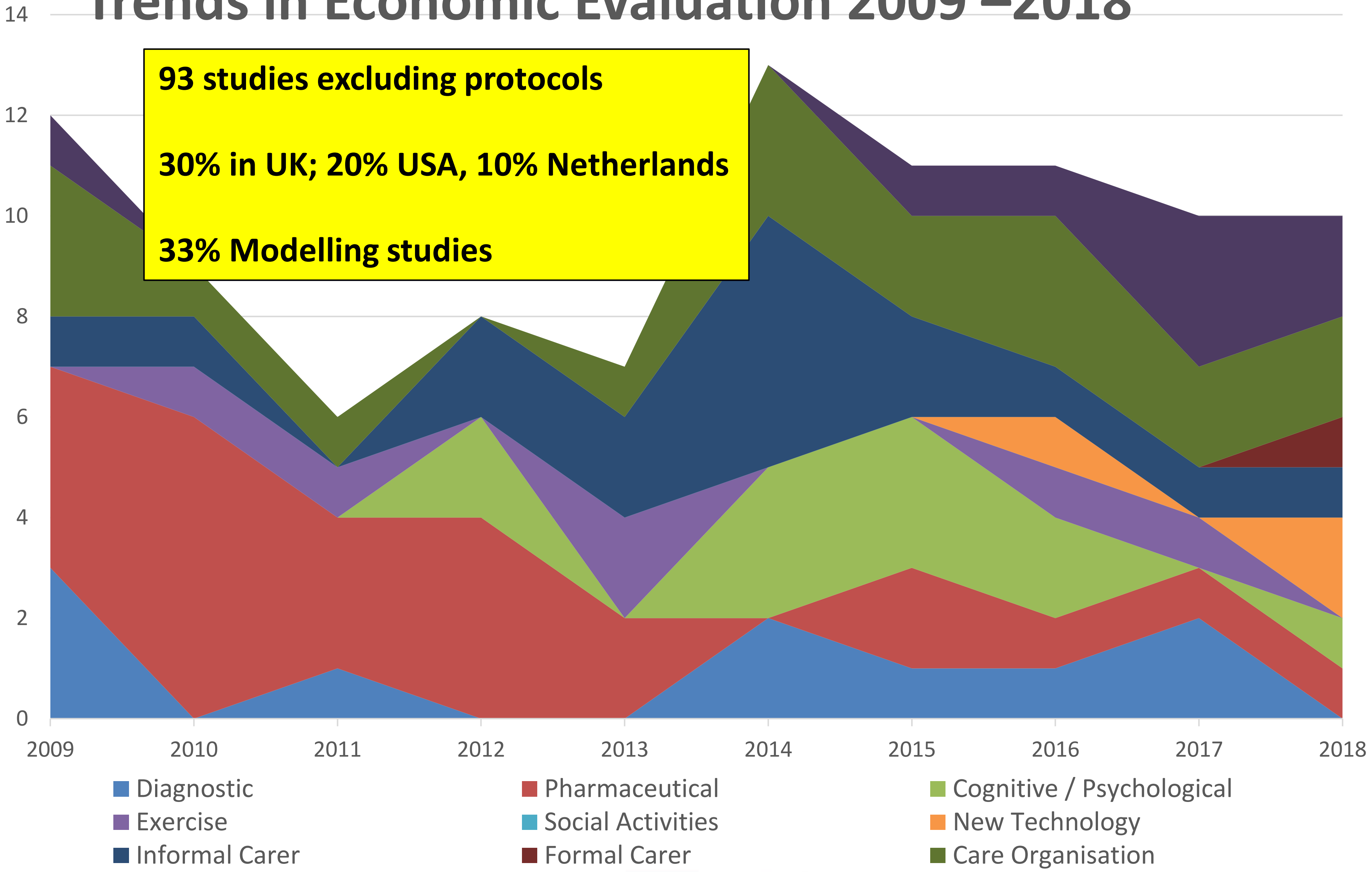
So….. searched CINAHL, Pubmed/Medline, Psychinfo, Econlit, EMBASE, SCIE Social Care Database 2009 - 2018

Trends in Economic Evaluation 2009 –2018

93 studies excluding protocols

30% in UK; 20% USA, 10% Netherlands

33% Modelling studies



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Observations

- Surprisingly limited evidence base
- Few replication studies
- Issues with transparency of reporting
- Increase in non-pharma focused evaluation e.g. more on informal carer support, psychological interventions
- Protocols now confirm increased interest also in new technologies
- Many opportunities to retrospectively build in econ analysis & support policy making

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Legacy Model

Raphael Wittenberg, Bo Hu, Amritpal Rehill
and MODEM team

Purpose of legacy model

- A publicly available web-tool to enable people to access the findings and outputs of the project and to make their own projections of expected outcomes and costs
- Tool designed for service commissioners, providers, advocacy groups, individuals and families
- One purpose will be to help strategic decision-makers and commissioners to use local data to assess needs and plan services for people with dementia

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Outputs of legacy model

The model outputs will comprise projections to 2030 of:

- Numbers of older people with dementia (prevalence), number of people experiencing onset (incidence);
- Numbers receiving unpaid care, health services, community social care services and residential care;
- Expenditure on care for older people with dementia by the NHS, local authorities and service users themselves

Under current care patterns and scenarios where cost-effective interventions are more widely diffused

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Capabilities of legacy model

The model will allow users to:

- Select their local authority to run local projections
- Enter local data about current numbers of service users
- Test the impact of variant assumptions about trends in dementia prevalence rates
- Test the impact of local plans to make specified interventions more widely available

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MODEM Reference group of users and carers
Our views on care and support

Margaret Dangoor

(Some key points from group discussions - May 2018)

Organisation barriers

Divisions between health, social care and voluntary sector – **inhibit patient-centred care coordination**

'We need joined up thinking'

Commissioned Services

Consultation please!

'Designed and chosen by us – not them'

Services that recognise individual and changing needs along the journey

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Clinical issues

People referred to secondary care (memory clinic) early, more likely to access **information and support**.

GPs sometimes perceived as a barrier to early referral

'Lottery of diagnosis'

Specialist consultant led support is valued

Social Care

Social workers role and assessment process remains confusing – care, finance, direct payments

'Is it all worth it, if above the eligibility criteria?'

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Respite care

Seldom meets the requirements of the individual with dementia **and** the carer; inflexible and expensive

'It is cheaper to pay for a holiday together'

Group peer support

Cited as the most beneficial longer term type of personal support

'Talking to, and sharing with people the same lived experience'

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Thank you

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Further information

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