

May 2015

modelling outcome and cost impacts
of interventions for dementia

MODEM

Tackling the Dementia Challenge

Dementia
Awareness
Week

How can we support and treat people with dementia in an acceptable way that's affordable?

Researchers from the London School of Economics and Political Science, Southampton University, Newcastle University, Sussex University and the International Longevity Centre-UK are carrying out a 4-year study that will project needs, supports and costs to help plan good, affordable dementia care up to 2040.

The MODEM project, funded by the NIHR and ESRC under their "Improving Dementia Care" funding initiative, aims to generate new evidence to inform policy and practice to better meet needs, promote health and wellbeing of people with affected by dementia and their carers, and achieve efficiency in the use of society's resources.



What is MODEM?

MODEM is a project to develop a comprehensive, integrative, quantitative set of models to estimate current and future needs, and the outcomes and costs of interventions aimed at meeting them.

It is drawing on methods from: economics, epidemiology, health services research, medicine, psychology, social policy, sociology, statistics, with the involvement of people with dementia and their carers.

An important outcome will be a publicly available web-based **LEGACY MODEL** so planners can project future costs under different assumptions about population needs, services and treatments. It should help commissioners, providers, charities, individuals and families to use all the knowledge we have gathered to plan for their particular circumstances and to improve the quality of life for people with dementia and their carers.

www.modem-dementia.org.uk

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@MODEMproject

Improving
Dementia Care
ESRC·NIHR

Where are we at now?

● Reviewing the evidence

We are conducting a review of reviews of interventions for dementia, as well as a systematic mapping of the literature on the effectiveness of dementia care interventions (including treatment, care models, interventions for carers, etc). The mapping will be used to identify the degree to which existing reviews cover the evidence. We will then produce reviews of areas not covered and update existing reviews. We will also highlight treatments and care models for which there is insufficient evidence.



The review will be used to identify effective interventions that will be modelled in MODEM, but it will also be a resource in itself

● Gathering the data

We are starting analyses of various existing datasets and trials that involve people with dementia, which will provide us with the data we need to build our models. As we need to combine information from different sources, which often use different measures to describe similar domains (for example levels of cognitive ability, or quality of life), we are also collecting data that will allow us to “cross-walk” between different measures.

The team at Sussex University have recently obtained ethical approval to survey a cohort of 300 people with dementia (stratified so that there are 100 people with mild, moderate and severe dementia) and their carers. The recruitment of people with dementia to the study has started and we are pleased that there seems to be great interest in participating.

● Developing the models

The teams at Newcastle and the LSE are making good progress in the development of the models. The epidemiological microsimulation model’s design has been finalised, and an early version of the macro-simulation model, which will act as a framework where the results of the other models will be integrated, is already functioning, although it will be under continuous improvement as we progress with the data analyses. We are also developing care pathways model to simulate the impact of specific interventions and a lifetime costs of care model.

Where are we at now?

● Understanding people's experiences

We are preparing to find out more about how interventions for people living with dementia and their carers work in practice by carrying out qualitative research using both focus groups and detailed interviews. We will be looking, in particular, to find out more about the experience of using interventions or types of care for which there is not much quantitative evidence. This work will be conducted both by the team in Southampton and the LSE. Ethical approval for the focus groups has been requested.

● Social interaction and cognitive functioning

Research is underway to better understand the relationship between social interaction and cognitive function. A first paper related to this work "Fertility history and cognition in later life among men and women in England" was presented by Sanna Read and Emily Grundy at the IAAG conference in Dublin in April 2015.

● Gender and older carers of people with dementia

Klara Lorenz has started her PhD, funded by the MODEM project, to investigate whether unpaid male and female carers aged 65 and above can expect to live well when providing care for a person with dementia.

The thesis will address the wellbeing of this carer group through quantitative and qualitative analysis and will place a specific focus on potential gender differences. It will also focus on the costs unpaid the carers incur and how these are influenced by age, gender, the stage of dementia and the presence of comorbidities.

Related projects

The team has been involved in various related studies, including a study that simulated future scenarios of dementia care which was presented at the [G7 First Global Dementia Legacy Event](#) on Finance and Social Impact Investment in Dementia, London, 19 June 2014:

Knapp M, Comas-Herrera A, Wittenberg R, Hu B, King D, Rehill A, Adelaja B (2014) *Scenarios of dementia care: what are the impacts on cost and quality of life? Report to the Department of Health, Personal Social Services Research Unit, London.* [Referenced in the Prime Minister's Challenge on Dementia 2020, 21 February 2015.](#)

We also carried out a study of the costs of dementia for the [Alzheimer's Society](#).

Meet our team



Derek Piggott



Derek is a member of the reference group. He commenced his flying career in 1942 and achieved the highest RAF qualification for a flying instructor. Later he became a glider chief instructor, trainer and test pilot. Derek is renowned worldwide and has lectured internationally and written eight books on gliding and gliding instruction. He has won many prestigious awards including an MBE for services to gliding. Derek at 92 years is still flying.



Raphael Wittenberg

Raphael is a Principal Research Fellow at PSSRU at LSE and Deputy Director of the Centre for Health Service Economics and Organisation (CHSEO) at the University of Oxford. At PSSRU, he leads a programme of research on financing long-term care, which aims to make projections of demand for long-term care for older people and associated expenditure to 2041. He also leads research on direct payments in residential care and on community care for older people and leads modelling work for the MODEM study on care for people with dementia.

More information on the team can be found on our website



Reference Group of people with dementia and carers

by Margaret Dangoor

Since the first meeting of our MODEM Reference Group of Users and Carers in September 2014, and as a member of the dementia and carers 'community', my diary has been full of activities keeping me in touch with people with dementia and their carers. My most direct contact is through regular attendance at two 'Caring Cafés where people with dementia and their carers are able to meet on an informal basis and where I chair 'Experts by Experience Carers' groups; the opportunity for peer support is an invaluable source of on-going support for carers. Another activity is as an Alzheimer's Society volunteer where once a month I accompany a group of people with dementia and their carers to the Royal Academy for an 'In Mind' conversation around a picture of the day.

Representational roles are many, including attending a Dementia Action Alliance 'Carers Call to Action' conference in October, a Queen's Nursing Institute carers' project in November and a Department of Health meeting in December to discuss the 'Development of a Dementia Vision to 2020. As a Dementia Champion I have given talks in care homes to enable staff and others to become Dementia Friends. In February I spoke at an RCN event to talk about the practical experience of being a carer of an individual with dementia. That month I also attended a King's Fund conference on leading change in dementia diagnosis and support. At a national conference to be held in March I shared a 'slot' on the programme with our local director of public health to talk about the creation of dementia friendly communities.

With the Care Act 2014 being introduced from April this year there is much to do at local level, representing the views of people with dementia and their carers on co-production working groups, hoping to influence the way the requirements of the Care Act are implemented.

I am looking forward to meeting up with members of our Reference Group of Users and Carers (RGUC) at our next meeting on 29 July; as the research project progresses there will be opportunities for representatives of the dementia community to join us round the table or attend workshops to hear about and contribute to the progress of the MODEM project

The project combines the expertise of researchers in simulation modelling, social gerontology, health and social care economics, clinical evaluations, qualitative methods and knowledge exchange

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Tell us what you think

What will dementia care look like in 2040?

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