The Dementia Evidence Toolkit

LAUNCH 19th JULY

Building on a Systematic Mapping of the literature on effectiveness of interventions in dementia carried out for the MODEM project, and with thanks to additional funding from the Economic Social Research Council (ESRC), we are delighted to announce the launch of the Dementia Evidence Toolkit on the 19th of July.

The Toolkit is a web-based resource consisting of:

- A searchable coded bibliographic database of 3,000 empirical papers and 700 systematic reviews on interventions for the treatment, care and support of people with dementia and carers, comprising the period between 2009 and June 2015.
- Plain language summaries of the evidence on the effectiveness (and cost-effectiveness) of key care and treatment interventions.

The aim of the Toolkit is to provide easy access to scientific evidence of dementia care and treatment and to provide clear and rigorous information to people living with dementia, family and other unpaid carers, staff working in the health and social care sectors, local and strategic decision-makers and researchers.

The Toolkit builds on a systematic mapping of literature carried out as part of the MODEM research project. This additional funding from ESRC has enabled the team to make the database publicly available, to develop the methods and first examples of the evidence summaries, and to consult with people living with dementia, carers, service providers, commissioners, third sector organisations and other academics.

The team are very grateful to people with dementia, unpaid carers, local commissioners and care professionals who have given their time to help shape the contents, style and accessibility of the summaries. We also sought their views about the key interventions that we should prioritise.

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Cohort study on track to recruit participants for longitudinal study

More than 200 people with dementia and their carers have been recruited to take part in a new longitudinal study as part of the MODEM project.

A team of researchers at Brighton and Sussex Medical School are conducting the interviews, and are on track to reach the target of 300 participants by August 2016.

The team is awaiting final confirmation from 60 more people who have already expressed interest in the study.

The interviews will provide valuable data on the needs, care and outcomes of a cohort of people with dementia and their carers and how these change over time. At present, there is a particular focus on recruiting people with more severe dementia, regardless if they are living in a care home or in the community.

The programme has been boosted by JOIN DEMENTIA RESEARCH, an online hub which matches people with dementia willing to take part in studies with researchers working in the area.

The initiative is being funded by the National Institute for Health Research.

Dr Nicolas Farina, Research Fellow in Dementia at the Centre for Dementia Studies at Brighton and Sussex Medical School, said:

“Join Dementia Research has been a very useful tool for recruitment. We have now approached every participant that is eligible in the Sussex area, and the response has been very positive.”

Watch a video about Join Dementia Research at www.youtube.com/watch?v=rje7jisykEw&feature=youtu.be
NEW PUBLICATION

Sanna Read and Emily Grundy have published the article: Fertility history and cognition in later life in the *Journal of Gerontology, Series B* http://eprints.lse.ac.uk/65366/

Risk factors of cognitive impairment

Interim findings from a MODEM research project suggest that the social activities of individuals and their social networks help to maintain steady levels of cognition, in addition to their education.

**THE SOCIAL PARTICIPATION WORK PACKAGE (WP5)** is exploring the characteristics influencing cognition at the age of 50. Researchers from the University of Southampton are using data from the National Child Development Study (NCDS). This is a longitudinal data set which follows the lives of 17,000 adults born in a single week in 1958.

The team have been investigating a hypothesis drawn from the literature, that the following factors might be associated with cognition at 50 years old: health behaviours, social support and social net in adolescence, and socioeconomic characteristics during childhood and adulthood.

Researchers led by Dr Jitka Pikhartova and Professor Ann Bowling used linear regression in multivariable analysis to explore the independent associations between possible risk factors and cognition at age of 50.

Positive associations with cognition were found with participation in civic activities at the age of 33 and 50, frequent participation in sporting activities at age 42, highest achieved qualification, and being female. On the other hand, having a manually working father at age of 11 and having at least two family members to whom respondents could turn for advice at the age of 33 were negatively associated with cognitive outcomes.
Batcho Notay

Batcho is a former carer and member of the MODEM reference group of users and carers. She gave up a career as a radiographer and cared for her mother, who had multiple health problems including dementia, over ten years. She is now involved in a wide range of voluntary roles such as supporting blind and deaf adults, and is an active member of local Healthwatch and carers forum groups. She is also a tutor with an Expert Patient Programme supporting people with long term health conditions.

Batcho is pleased to be able to contribute to the movement towards greater involvement of users and carers within research. She said: “The subject of dementia is very close to my heart and carers’ role needs to be highlighted. I feel very strongly that we need to be aware of the significant impact and toll that caring makes.”

Carol Jagger

Carol is the AXA Professor of Epidemiology of Ageing at Newcastle University. She is also Deputy Director and theme lead for ‘Ageing: Economic and Societal Impact’ in the Newcastle University Institute for Ageing. She has provided expert advice for the Office for National Statistics and the Scottish Public Health Observatory on Healthy Life Expectancy.

Carol is a Chartered Scientist, a Fellow of the Royal Statistical Society and the Gerontological Society of America and an Honorary Fellow of the Institute and Faculty of Actuaries. In her spare time she enjoys hiking, reading crime fiction and she is a bereavement supporter for her local hospice.

More information on the team can be found on our website.
Visit to day centres caring for people with dementia

In October 2015 a group of researchers visited two day centres in the London borough of Richmond, with a view to learning more about the way people with dementia are supported in the community.

The Homelink Day Respite Centre in Whitton and the Woodville Centre in Ham kindly welcomed the team, during what proved to be a fascinating day out, organised by Margaret Dangoor, PSSRU’s Research Involvement Manager.

At the WOODVILLE CENTRE, the researchers met people with dementia and their carers, and were given tours of the building by managers and volunteers working at the centre.

In the afternoon people from various organisations involved in dementia care talked to the team about the local support available, and there was an enjoyable tea party for invited guests. These included people attending the centre, their carers, three borough councillors, and senior managers from the London Borough of Richmond’s adult social services department.

Jenny Bailey, Manager of the Woodville Centre, said her staff and clients were “very pleased” to accommodate the visit:

“The main focus of the MODEM team visit to Richmond was to learn more about and experience a variety of local services and the team’s visit to Woodville was a great opportunity to share our day and exchange information.”

Meanwhile the HOMELINK CENTRE provided an interesting example of how nurse-led day care can potentially help to avoid acute health care costs. Some aspects of the care are delivered by volunteers, while nurses and three healthcare assistants are on hand every day to deliver regular healthcare monitoring for the guests. Qualified staff provide regular tests for the clients covering blood pressure, urinary tract infection and blood sugar level; the practitioners keep in regular contact with the guests’ GP surgeries to inform them of any problems.

The chief executive officer of the Homelink centre, Sue Hodder, said it was “lovely” to receive the MODEM team. She said:

“I feel to be able to visit a centre of excellence like ours enabled the team to see how things really operate on the front line and in particular to see how a local charity here in Twickenham plays such a highly professional role in caring for people with dementia.”
The project combines the expertise of researchers in simulation modelling, social gerontology, health and social care economics, clinical evaluations, qualitative methods and knowledge exchange.
What will dementia care look like in 2040?

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