APPG BRIEFING

PUBLISHED NOVEMBER 2017

E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

HIGHLIGHTING RESEARCH FINDINGS AND THEIR RELEVANCE IN KEY POLICY AREAS

ESRC-NIHR Living well with dementia initiative

The Economic and Social Research Council and the National Institute for Health Research (NIHR) jointly fund a £20 million dementia social science research initiative on interventions and care – the world's largest social science research programme on dementia and care.

The initiative funds six research grants covering different aspects of living with dementia: maintaining independence, living with vision impairments, managing agitation in care homes, living well with dementia, neighbourhood living, and modelling outcome and cost impacts of interventions for dementia.

Managing agitation and raising quality of life in dementia (MARQUE)

www.ucl.ac.uk/psychiatry/marque

The MARQUE project will increase theoretical knowledge of dementia, agitation and how people with dementia and their carers experience these; reduce agitation in people with moderate and severe dementia; and mentor existing and train new dementia researchers.

The research will involve observing and interviewing a wide range of people with dementia and those who care for them at home, in care homes and at end of life. This information will be used to develop, test and implement a training manual for staff, which will be tested in a randomised controlled trial in 20 care homes.

The research will lay the foundation for a pilot home intervention, and development of a manual to improve people with dementia's end of life, to be piloted in four nursing homes with staff, family and residents.

Principal investigator:
Professor Gill Livingston, University College London

Improving the experience of dementia and enhancing active life (IDEAL)

www.idealproject.org.uk

Enabling people with dementia and carers to 'live well' with the condition is a key UK policy objective. The aim of this project is to identify what helps people to live well, or makes it difficult to live well, in the context of having dementia or caring for a person with dementia.

Over a two-year period, 1500 people with early-stage dementia will be recruited to the study, together with a carer wherever possible. All the participants will be visited at home initially and again 12 months and 24 months later, while a smaller group will be interviewed in more depth.

The findings will lead to recommendations about what can be done by individuals, communities, health and social care practitioners, care providers and policymakers to make services more effective in increasing quality of life.

Principal investigator:
Professor Linda Clare, University of Exeter

Modelling outcome and cost impacts of interventions for dementia (MODEM)

www.modem-dementia.org.uk

As the UK population ages over the coming decades, the number of people with dementia will increase considerably. This study will collect information on care and needs from 300 people with dementia and their carers, using the data to simulate a nationwide rollout of beneficial care interventions.

The researchers will make projections of how many people there will be with dementia over the period to 2040, what family or other unpaid support they are likely to have available, and what it will cost to provide care services.

A web-based modelling tool will enable commissioners, providers, charities, individuals and families to make projections of future costs under different assumptions about population needs, services and treatments.

Principal investigator:
Professor Martin Knapp, London School of Economics and Political Science

Seeing what they see: Compensating for cortical visual dysfunction in Alzheimer's disease

www.ucl.ac.uk/dementia-vision

Alzheimer's disease (AD) is often misperceived as a disorder largely or solely of memory, but the disease also affects the visual areas of the brain leading to problems seeing what and where things are.

This programme aims to deliver interventions in care homes and the homes of people with dementia that compensate for the effects of dementia-related vision loss; evaluate how visual compensatory strategies impact on quality of life; and gather insights from individuals with Posterior Cortical Atrophy (PCA) and carers to identify and understand visual impairment in typical AD – offering a unique perspective on the AD patient's view of the world.

Principal investigator:
Dr Sebastian Crutch, University College

Neighbourhoods and dementia: a mixed methods study

www.neighbourhoodsanddementia.org

The Neighbourhoods and Dementia study aims to help us understand more about what it is like to live with dementia in an everyday context, focusing on the local neighbourhood and networks of people with dementia and their care partners – looking at the interaction between people, spaces and places. The eight work programmes promote closer relations and working between professionals, lay people and people living with dementia and their care partners.

The Neighbourhoods study includes 10 research organisations with the Center for Dementia Research in Sweden as the international partner, 14 project partners and strong involvement from advocacy support groups.

Principal investigator:
Professor John Keady, University of Manchester

Promoting independence in dementia (PRIDE)

www.ucl.ac.uk/psychiatry/pride

This programme aims to investigate how lifestyle changes can reduce risk of dementia, understand the social impact of dementia, and develop a social intervention to enhance independence for people with dementia.

Data from the English Longitudinal Study of Ageing cohort – which followed 10,000 older people over 10 years – will be analysed to determine dementia prevalence amongst older people and the potential impact of lifestyle changes such as exercise on cognitive abilities. The research team will explore people's concerns and experiences when referred to memory services, at diagnosis, and over the following two years.

Principal investigator:
Professor Martin Orrell, University of Nottingham

The Economic and Social Research Council is the UK's leading agency for research funding and training in economic and social sciences. www.esrc.ac.uk @esrc Email: comms@esrc.ac.uk