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The number of people living in the United Kingdom (UK) with dementia is rising. People with dementia, society, and health/social care agencies are reliant upon informal carers, such as friends and family, to provide care and support.  In 2015 the number of UK primary informal carers for people with dementia was estimated at more than 670,000.

Having a caring role can have a huge impact on well-being, quality of life, and finances, yet without these informal carers people with dementia would be dependent upon health and social care services and government costs would be increased greatly. It is important therefore that we find a way of measuring the quality of life of carers so that we can provide them with the right support at the right time. DECIDE (Dementia Carers Instrument Development), is a new research project, which aims to develop a new questionnaire to measure the quality of life of people caring for someone living with dementia.

This website will provide up to date information about the DECIDE project, as well as useful links to the many organisations that are supporting it. It is hoped that the results will help provide an easy and accurate way of assessing the needs and quality of life of carers of people with dementia, and to help to identify carers most at need, as well as informing decision making concerning government spending.

# Background

Although the prevalence of dementia in the UK has decreased over the last 20 years, with the ageing population the absolute number of people in the UK with dementia is predicted to reach 850,000 by 2015 (Alzheimer's Society figures).

The economic cost of care is enormous and rising. The estimate of the current UK annual economic impact of dementia is £26.3 billion, with just under half attributed to the care provided by 'informal carers'. The government has previously responded to this challenge by publishing a series of policy documents with the aim of improving dementia care.  In addition, the National Institute for Health and Care Excellence (NICE) published a quality standard for supporting people to live well with dementia,

and guidance for commissioning dementia care.  The role of carers has been recognised by NICE and by NHS England.

# What are we doing and why are we doing it?

Carers may experience the impact of looking after someone with dementia on their psychosocial well-being, physical functioning, general health and health behaviour, as well as employment and finances.  Maintaining carer well-being and quality of life is important not only for the carers and the person being cared for but also for society as a whole.

There are numerous quality of life questionnaires and many of these have been used in dementia carer assessment.  However, some are too general and do not pick up on subtle changes in carer quality of life.  Others are too long or have unreliable ways of working out scores.

Through the DECIDE project we will improve our understanding of the needs of carers. Using this knowledge we will develop a new reliable and valid measure, which can be used to assess the needs of carers of people with dementia who are living in the community, including those in sheltered or extra-care housing.   The measure will be brief and easy to complete making it useful in individual carer assessment as well as being used to inform service planning and potentially in service valuation.

The results from the study will be available for other researchers, clinical, social and voluntary service organisations, practitioners and government agencies, for use in future evaluation projects.  The research findings will be promoted and presented at national and international academic conferences, and through medical and specialist journals.

# Who is involved?

 To deliver this novel research project DECIDE brings together a highly experienced group with diverse backgrounds and complimentary skills.  The diversity of the team allows for an interesting and innovative collaboration and is led by Dr Penny Wright of the University of Leeds.  The full list of people involved in the project can be found in the meet the team section of this site.  The project team will also include an advisory group of four carers of people with dementia, identified via Carers Leeds, who will support the study and share their experiences and extensive knowledge.

DECIDE has six project partners :

- Bradford District Care Trust
- Alzheimer's Society (Yorkshire)

- Carers UK
- Alzheimer's Society
- Dementia UK
- Young Dementia UK

The study also brings together researchers from five leading universities, led by the host research organisation, the University of Leeds.

# How will the project work?

The project has two parallel workstreams. Each of these Workstreams will involve a number of phases :

Workstream 1: Questionnaire Development

Workstream 1 follows standard procedures for developing a 'needs based' questionnaire, which are:

Phase 1: Item Generation

This will involve interviewing a sample of carers from West Yorkshire. The people interviewed will represent a wide range of carer situations and backgrounds. The aim of the interviews will be to help identify the types of challenges and rewards that carers are experiencing in their role. From these interviews a question pool (known as an item pool) will be formed. Where possible these questions will contain words and phrases spoken by the carers themselves during their interviews.

Phase 2: Item Refinement

In a second study another group of carers will be asked to complete the item pool questions and then, be asked to tell us about their understanding, the acceptability and the meaningfulness of the 'items' emerging. The item pool will be reviewed after this and refined to create a final item pool.

Phase 3: Psychometric evaluation of the item pool leading to development of an item bank and brief a Quality of Life measure

This third study will involve over 400 carers, recruited in part from another study called 'IDEAL' and others recruited via health and social care services. The carers will complete the final item pool from phase 2 and some other questions. Their responses will be analysed by the research team resulting in a reliable and valid item bank and a brief Quality of Life questionnaire.

Workstream 2: Methodological Issues in Valuation

Study 1: Comparison of health state values in carers and non-carers

We will use a measure called EQ-5D (a standardised questionnaire for use as a measure of health outcome) to establish whether carers think about health in the same way as the general public, or whether they value certain aspect of health differently. A sample of carers will be matched to a sample of the general public who share similar characteristics (age, ethnicity etc).

In a second part, an online survey will be used to measure and compare how health is valued by three groups: individuals who are carers or close family members of people with dementia; individuals who are carers of people with other forms of long-standing health or social care problems; individuals from the general public.

Study 2: Calibrating Carer Quality of Life Items against the EQ5D:

We will select items from the Quality of Life measure developed in Workstream 1 and measure the responses/scores against the responses/scores from EQ-5D. The purpose of this study will be to see how the responses to these specific questions compare.

Study 3 : Direct Valuation of the Carer Quality of Life Items:

A second online survey will be designed, using the same items in Study 2. This will then be used to create hypothetical carer profiles showing carers with different health and quality of life states. These carer profiles will be presented in pairs to a sample of carers and a sample of the general public. They will be asked to select which carer profile they prefer. This will let us know how the general population preferences compare to those of carers.

# Who is the funder/sponsor?

This study is jointly funded by the Medical Research Council and the National Institute for Health Research, who put out a call to researchers under a methodology highlight notice: https://www.mrc.ac.uk/funding/how

The study sponsor is the University of Leeds.