

SIDECAR

Scales measuring the Impact of **DE**mentia on **CAR**ers



WHAT IS SIDECAR

SIDECAR stands for **S**cales measuring the **I**mpact of **D**ementia on **C**ARers. It is a questionnaire designed to measure the quality of life of carers of people with dementia. The questionnaire is made up of 3 scales, one primary and two secondary. Each one measures a different 'theme'.

We have listened to the voices of 42 carers of people with dementia to help us understand what life is like for them. We hope that SIDECAR will be used to help identify carers who may need help to get them the right support at the right time.

HOW WAS SIDECAR DEVELOPED

There were 3 stages:

Stage 1: Carers were interviewed to ask them what life was like for them. Once we found common themes in what they said, and using their actual words, we ended up with 70 questions with an agree/disagree response option.

Stage 2: We asked carers in England and Wales to answer the 70 questions. We used a number of different methods and tests to analyse their answers and work out which questions we should keep for the new quality of life questionnaire. Three SIDECAR scales were developed and tested (SIDECAR A, B, C)

Stage 3: SIDECAR A was given to health economists involved in the study so they could carry out their own valuation work on it. This involved looking at how dementia carers assessed their own health-related quality of life compared to the general public. We hope that in the future the questionnaire can be used to measure the cost-effectiveness of interventions aimed at helping dementia carers.



HOW DO WE ACCESS IT?

You will be able to access SIDECAR through the University of Leeds website. It is important this is done in a structured way so we will be asking people to register through the University's licensing platform. A link to that platform will be available shortly and details of this will be provided through the study website www.decideproject.co.uk.

IS IT FREE TO ACCESS?

SIDECAR is free for everyone except for commercial companies, providing it is accessed through the Leeds University platform

WHO CAN USE IT?

The SIDECAR questionnaires will be available for anyone to use. We hope they will be used for individual carer assessment services, research into carer needs, and in the future for carer valuation work.

DATA SHARING

The data collected in stages 1 and 2 will be available for academics to request through the University of Leeds research data repository at: <https://doi.org/10.5518/433>.

HOW WAS THE STUDY FUNDED AND WHO WAS INVOLVED?

The study was funded by the Medical Research Council (MRC) and the NIHR (National Institute for Health Research). It brought together a highly experienced group and was led by Dr Penny Wright of the University of Leeds. There were five project partners:

- Bradford District Care Trust
- Alzheimer's Society
- Carers UK
- Dementia UK
- Young Dementia UK

The study involved co-investigators from six leading Universities:

- University of Leeds (Alan Tennant, Penny Wright, Paul Kind)
- Bangor University (Zoe Hoare)
- University of Birmingham (Hareth Al Janabi)
- University of Bradford (Jan Oyebode)
- University of Cambridge (Carol Brayne)
- University of Exeter (Linda Clare)

And collaborator Val Hewison, CEO of Carers Leeds.

HELP US SPREAD THE WORD



Please help us by spreading the word about SIDECAR to as many people as possible. Use **#decidestudy**. You can follow **@decidestudy** for updates.

SOME PHOTOS FROM OUR END OF STUDY EVENT

SIDECAR was officially launched at an event in Leeds on 18th September which included presentations from people involved in the DECIDE study and invited speakers from other organisations.



Official welcome by University of Leeds Vice-Chancellor Sir Alan Langlands



DECIDE's lead Investigator Penny Wright gives an introduction to the study



A brief introduction by Val Hewison, CEO of Carers Leeds



Andrew Middleton talks about his personal experience as carer to both his parents



Professor Paul Kind, DECIDE Workstream 2 lead



Dr Karen Harrison-Dening, Head of Research & Evaluation, Dementia UK



Jen Kenward, Experience of Care Lead, Community Primary & Integrated Care, NHS England



Richard Popplewell, Chair of NHS Digital Indicators Governance Board



Questions and discussion with the presenters