Evi-Dem: Translating evidence of costs and benefits of home support in later stage dementia

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From a previous dementia programme funded by the National Institute for Health and Care Research (NIHR) we have unique data concerning people in later stage dementia and their carers receiving support at home.

In this project we will re-analyse this data, providing evidence of the costs and benefits of different services for different groups:

- 518 people with dementia and their carers living at home in 17 areas of England
- Receiving 40 different types of support including:
  - healthcare - home nursing, hospital care
  - social care - respite, day care, aids, social work
  - Dementia Support Workers, advice workers
  - Occupational therapy

What kinds of services offer the most benefit and for whom? What are their costs?

**Our team** are exploring these issues; we are to create and share the data and findings with the help of our research partnership:

**Paul Clarkson** is Senior Lecturer in Social Care, University of Manchester and study lead. He is an experienced researcher in the field of dementia care

**Sue Davies** is Research Associate in Social Care at the University of Manchester and an experienced analyst and dementia researcher

**Gemma Shields** is a health economist and experienced analyst and methodologist

**Celia Toole** is a public contributor and CEO of Sight & Mind CIC, providing support to people with dementia and their carers with sensory impairments

**Ian Sheriff** is Partnership Lead for Dementia, University of Plymouth and member of the Prime Minister’s Challenge Group on Dementia

**Simon Kaye** is Research & Innovation Lead, Pennine Care NHS Foundation Trust
We have been consulting with a range of stakeholders and partners, including dementia carers, to discover the best ways to present our data and findings.

They tell us that our findings should be presented in an accessible way; through infographics and pictures and that the content should be interactive; permitting users to test out effects of different assumptions.

For instance, those accessing the data and findings may want to see the costs and benefits for particular people – male carers or people living in rural areas for example.

Content available on our user website should also confirm to accessibility standards, e.g. the Web Content Accessibility Guidelines (WCAG) 2. Therefore, we have decided to implement the following features:

**Features of our data**

- **The information will be clearly presented, useable to different audiences.** Family carers, in particular, must be able to understand our findings, despite them being underpinned by robust research analysis.

- **Users must be able to navigate the material and interact with it to answer questions they are particularly interested in.**

- **Users should be able to access the content on multiple devices.** The information should be up to date and relevant.

- **As well as being useable the information should be robust.** Costs, for example, should be based on the full costs of care. Any metrics (e.g. those of well-being), should be explained clearly.
Our Research Partnership

We are working with a number of individuals and organisations to get our evidence out there and influence commissioning and decision-making of multiple stakeholders, including family carers:
Our partnership will help to get our findings from the data out there to influence commissioners, policy makers and provide a resource for family carers. Carers will be able to judge the effects of different services on their relatives’ and their own well being. They will be able to balance this with data on the costs of services and the potential costs of the care they might provide.

The data and findings we provide will be provided in an interactive format. Carers and commissioner’s will be able to see if well being changes from receiving particular combinations of services or for certain groups, e.g. people with dementia living alone with remote carer support or those with particular difficulties.

For more information about the Evi-Dem project and to keep updated please contact us:

- evidem@manchester.ac.uk
- Speak to members of our team at a series of workshops and events: to be announced

Our Effective Home Support in Dementia Care website gives information from our previous Dementia programme and will be the site where our Evi-Dem findings will be presented in an interactive format: https://sites.manchester.ac.uk/home-support-dementia/

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