

The DECIDE study: dementia carers making informed decisions

Submission date 03/05/2016	Recruitment status No longer recruiting	☐ Prospectively registered
		☐ Protocol
Registration date 14/06/2016	Overall study status Completed	☐ Statistical analysis plan
		☒ Results
Last Edited 10/07/2023	Condition category Mental and Behavioural Disorders	☐ Individual participant data

Plain English summary of protocol

Background and study aims

Dementia is a common condition caused by the ongoing decline of the brain and its abilities with age. People with dementia and their relatives find it difficult to make decisions about whether they should live in a care home. The aim of this study is to develop and test a decision aid, known as the 'DECIDE manual', for carers of people with dementia to use when making decisions about living arrangements and place of care for their relative.

Who can participate?

Family/friend carers of people with dementia

What does the study involve?

Participants are randomly allocated to one of two groups. One group receives the 'usual treatment', in this case being given a copy of the Alzheimer's Society factsheet 'Selecting a care home'. The other group receives the DECIDE manual, which the researcher takes participants through at the initial interview. All participants answer questions about decision-making and how they care currently feeling at the initial assessment, and 1 week and 10 weeks later.

What are the possible benefits and risks of participating?

We cannot promise the study will help participants but the information we get might help improve the support offered to carers of people with dementia and help healthcare staff discuss living arrangements and place of care with families in the future. We do not anticipate that there will be any disadvantages to taking part except for the inconvenience of making time for the interview, but it is possible that some topics discussed concerning the stresses of caring may be upsetting, so participants will be given details of appropriate, independent support services.

Where is the study run from?

This project is based at University College London and participants will be recruited from four memory clinics across three London boroughs: Camden Memory Service and Islington Memory Assessment and Treatment Service within Camden and Islington NHS Foundation trust; Haringey Memory Service within Barnet, Enfield and Haringey Mental Health trust and Tower Hamlets Diagnostic Memory Clinic within East London NHS Foundation trust.

When is the study starting and how long is it expected to run for?

August 2014 to April 2016

Who is funding the study?

UCL IMPACT studentship and the Division of Psychiatry (UK)

Who is the main contact?

Kathryn Lord

Contact information

Type(s)

Public

Contact name

Miss Kathryn Lord

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Contact details

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Additional identifiers

Study information

Scientific Title

The DECIDE study: dementia carers making informed decisions

Study objectives

Family carers who receive the DECIDE manual intervention will find the resource relevant and useful and to evaluate trial recruitment and retention in preparation for a full, pragmatic trial of the intervention.

Ethics approval required

Old ethics approval format

Ethics approval(s)

1. National Research Ethics Service Committee North East – Newcastle & North Tyneside 2, January 2015; REC Reference: 15/NE/0015
2. Local approval was obtained from all regions where the study was conducted (East London and Camden and Islington NHS Foundation Trusts and Barnet, Enfield and Haringey Mental Health NHS Trust)

Primary study design

Interventional

Study design

10-week pre and post design

Study type(s)

Other

Health condition(s) or problem(s) studied

Carers of people with dementia

Interventions

Half of the cohort will receive the DECIDE decision aid we have created, the other half will receive 'treatment as usual'. In this instance that will be telling carers that if they want any further information they should speak with their healthcare professional.

Intervention Type

Behavioural

Primary outcome(s)

The proportion of family carers who receive the DECIDE manual who report finding it relevant (defined a priori as a score of 4 or 5 on a 5 point Likert scale) and the proportion of family carers who receive the DECIDE manual who report finding it useful (defined a priori as a score of 8, 9 or 10 on a 10 point Likert scale).

Key secondary outcome(s)

To test the secondary hypothesis that family carers who receive the DECIDE manual intervention will report lower scores on the total Decisional Conflict Scale score and Informed sub-scale score, when compared to family carers in the treatment as usual group 10 weeks post baseline.

Completion date

01/04/2016

Eligibility**Key inclusion criteria**

1. Current, unpaid, main informal carer (e.g. a family member or friend in regular contact who is either next of kin or a 'key decision maker')
2. English language skills sufficient to participate in interviews. Whilst it is acknowledged that that the ideal would be to use the first language of all potential participants unfortunately there were not funds to provide interpreters

Participant type(s)

Carer

Healthy volunteers allowed

No

Age group

Adult

Lower age limit

18 Years

Sex

All

Total final enrolment

41

Key exclusion criteria

1. Carers under the age of 18 years
2. Carers where there are clinical concerns that may preclude them from being approached such as severe physical or mental illness or lack of capacity to give informed consent

Date of first enrolment

01/05/2015

Date of final enrolment

01/01/2016

Locations**Countries of recruitment**

United Kingdom

England

Study participating centre

University College London

United Kingdom

W1T 7NF

Sponsor information**Organisation**

University College London (UK)

ROR

<https://ror.org/02jx3x895>

Funder(s)

Funder type

University/education

Funder Name

Project that is part of a fellowship/personal award/research training award - PhD studentship funded by UCL IMPACT Award, cofunded by UCL Division of Psychiatry (Previously Mental Health Sciences Unit)

Results and Publications

Individual participant data (IPD) sharing plan

IPD sharing plan summary

Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article		02/02/2017	10/07/2023	Yes	No
HRA research summary			28/06/2023	No	No