# Effective home support dementia care

Submission date	<b>Recruitment status</b> No longer recruiting	[X] Prospectively registered		
25/07/2016		[X] Protocol		
Registration date	Overall study status	Statistical analysis plan		
29/07/2016	Completed	[X] Results		
<b>Last Edited</b> 30/08/2023	Condition category  Mental and Behavioural Disorders	Individual participant data		

## Plain English summary of protocol

Background and study aims

Dementia is a common condition in the aging population. People with dementia have difficulties with mental processes such as memory, language, reasoning and identifying people and objects, which become progressively worst over time. People are now living longer, meaning that dementia represents a significant public health and care challenge. About 60% of people with dementia live in their own homes but finding the best ways of helping them to live well at home and supporting their carers is a challenge. Although more innovative home support services, from the NHS, social care and voluntary organisations exist in some areas, they are often underdeveloped. The study will be for those in early stage dementia, receiving care through memory clinics. The aim of this study is to evaluate the effectiveness of memory aids (a tool used to trigger memory), delivered by Dementia Support Practitioners (DSPs).

#### Who can participate?

Adults aged 50 years and over with early stage dementia who are under the care of a participating memory clinic or equivalent.

#### What does the study involve?

Practices are randomly allocated to one of two groups. Those in the first group receive specialist advice, information and memory aids from DSPs, as well as usual care from the memory clinic or equivalent that they attend. The memory aids pack includes a calendar or clock, whiteboard with electric time, and 'post-it' note dispenser. Those in the second group receive usual care from memory clinics with a general guide to dementia for patients and carers. Participants and their carers are visited at the start of the study and then three and 12 months later to be interviewed about their opinions, quality of life and use of services in order to establish the effectiveness of the DSP program.

What are the possible benefits and risks of participating?

Participants may or may not benefit from participating in the treatment from the DSP. If participants are not chosen to take part in the treatment, there may be no direct benefits from taking part in the study. However, the information participants provide will help to strengthen the evidence for developing more appropriate support at home for those in early stage dementia. There are no notable risks involved with participating in this study.

Where is the study run from? Nine Memory clinics or Older Adult Services in England (UK)

When is the study starting and how long is it expected to run for? July 2015 to September 2018

Who is funding the study? National Institute for Health Research (UK)

Who is the main contact? Dr Paul Clarkson paul.clarkson@manchester.ac.uk

# **Contact information**

## Type(s)

Scientific

#### Contact name

Dr Paul Clarkson

#### **ORCID ID**

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#### Contact details

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# Additional identifiers

EudraCT/CTIS number

IRAS number

ClinicalTrials.gov number

Secondary identifying numbers 31288

# Study information

#### Scientific Title

Effective home support in dementia care: Project 2.1 dementia early stage cognitive aids new trial

#### Acronym

**DESCANT** 

#### Study objectives

The aim of this study is to evaluate whether memory aids, delivered by Dementia Support Practitioners (DSPs), are effective and cost-effective.

#### Ethics approval required

Old ethics approval format

#### Ethics approval(s)

North West - Haydock Research Ethics Committee, 20/06/2016, ref: 16/NW/0389

#### Study design

Randomised; Interventional; Design type: Treatment, Process of Care, Device, Rehabilitation

#### Primary study design

Interventional

#### Secondary study design

Randomised controlled trial

#### Study setting(s)

Hospital

## Study type(s)

Treatment

#### Participant information sheet

Not available in web format, please use the contact details below to request a patient information sheet

### Health condition(s) or problem(s) studied

Dementia

#### **Interventions**

Randomisation will take place after baseline interviews with consented participants but before data entry in MACRO4, the data entry database used in the study. On receiving completed screening forms and baseline interview schedules, the Trial Manager will complete a randomisation request form and email this to the Trials Unit (Swansea Trials Unit - STU). The participant will then be randomised by the Assistant Trial Manager at STU who will email the Trial Manager with a PDF with details of the allocation. Participants will be allocated on a 1:1 basis into Intervention: Dementia Support Practitioner – DSP or Comparator: Treatment As Usual – TAU without DSP.

Comparator: Participants will receive a general guide to dementia for patients and carers as well as treatment as usual (TAU) in the form of support from their carers with or without help from memory clinic staff, post-diagnostic counselling and advice, and specialist follow-up.

Intervention: Dementia Support Practitioners (DSPs) will augment TAU with specialist advice, information and memory aids. They will dispense appropriate aids; and provide training in using

these aids and general advice about improving memory. Their standard pack of memory aids will include: calendar or clock, whiteboard with electric time, and 'post-it' note dispenser, with a budget of £150 per participant. Support and follow-up will seek to ensure correct use of the aids. DSPs will work alongside any existing support and offer the memory aids in addition. The total duration of treatment will be 4 weeks.

For participants in both groups, follow up will be at 3 and 12 months after baseline (referral from memory clinic).

#### Intervention Type

Other

#### Primary outcome measure

Activities of Daily Living (ADLs) are measured using the Bristol Activities of Daily Living Scale (BADLS) at baseline, 3, and 12 months.

#### Secondary outcome measures

- 1. Cognitive function measured using the Standardised Mini-Mental State Examination (S-MMSE) at baseline, 3, and 12 months
- 2. Quality of life measured using DEMQOL and DEMQOL-PROXY (carer rated) at baseline, 3, and 12 months
- 3. Health status measured using the EQ-5D-5L at baseline, 3, and 12 months
- 4. Service receipt measured using the Client Service Receipt Inventory and the Resource Utilisation in Dementia (RUD) at baseline, 3, and 12 months
- 5. Minor psychiatric morbidity in carers measured using the General Health Questionnaire (GHQ-12) at baseline, 3, and 12 months
- 6. Carer coping measured using the Short Sense of Competence Questionnaire (SSCQ) at baseline, 3, and 12 months
- 7. Carer rating of patients' performance of activities measured using the Revised Interview for Deterioration in Daily living activities in Dementia (R-IDDD) at baseline, 3, and 12 months 8. Patient quality of life measured using the ICECAP-O and CASP-19 at baseline, 3, and 12 months

## Overall study start date

01/07/2015

## Completion date

31/12/2019

# Eligibility

### Key inclusion criteria

Participants with dementia:

- 1. Aged 50 years or older
- 2. Under care of one of the trial memory clinics or equivalent
- 3. Within one year of their first attendance at that clinic
- 4. Dementia is of mild to moderate severity
- 5. Physically able to engage with the intervention, usually as judged by researcher
- 6. Clinically able to engage with the intervention, usually as judged by responsible clinician
- 7. Living in their own home, or sharing a home with relative (i.e. not in residential or nursing home at baseline)

#### Carers:

The primary person who feels responsible for, and supports, the person with dementia. They may be any age and may live with the person with dementia or independently.

#### Participant type(s)

**Patient** 

#### Age group

Adult

#### Sex

Both

#### Target number of participants

Planned Sample Size: 360; UK Sample Size: 360

#### Total final enrolment

468

#### Key exclusion criteria

Participants with dementia:

- 1. Individuals who are under 50 years of age
- 2. Advanced dementia, e.g. in late stages
- 3. Resident outside local authority boundary served by the service
- 4. Those currently undergoing emergency treatment or care

#### Date of first enrolment

12/09/2016

#### Date of final enrolment

15/04/2019

# Locations

#### Countries of recruitment

England

United Kingdom

# Study participating centre Stockport Memory Service

The Meadows Owens Farm Drive Offerton United Kingdom SK2 5EQ

# Study participating centre Tameside Memory Service

Etherow Building Tameside Hospital Fountain Street Ashton under Lyne United Kingdom OL6 9RW

# Study participating centre Oldham Memory Service

Forrest House Royal Oldham Hospital Westhulme Avenue Oldham United Kingdom OL1 2PN

# Study participating centre Rochdale Memory Service

Watergrove Day Hospital Birch Hill Hospital Union Road Rochdale United Kingdom OL12 9QB

# Study participating centre Bury Memory Service

The Ribchester Centre Bury United Kingdom BL9 0JT

# Study participating centre Havering Older Adults Services

Victoria Centre Pettits Lane Romford United Kingdom RM1 4HP

# Study participating centre Barking and Dagenham Older Adults Services

Broad Street Health Centre Morland Road Dagenham United Kingdom RM10 9HU

# Study participating centre Waltham Forest Memory Service

Red Oak Lodge Leytonstone London United Kingdom E11 4HU

# Study participating centre Redbridge Older Adults Services

Older Adult Mental Health Team Goodmayes Hospital Barley Lane Goodmayes United Kingdom IG3 8XJ

# Sponsor information

# Organisation

The University of Manchester

# Sponsor details

Faculty of Medical & Human Sciences Room 3.53 Simon Building Brunswick Street Manchester England United Kingdom M13 9PL +44 161 275 5436 lynne.macrae@manchester.ac.uk

# Sponsor type

Hospital/treatment centre

#### **ROR**

https://ror.org/027m9bs27

# Funder(s)

#### Funder type

Government

#### **Funder Name**

National Institute for Health Research

#### Alternative Name(s)

National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

## **Funding Body Type**

Government organisation

#### **Funding Body Subtype**

National government

#### Location

**United Kingdom** 

# **Results and Publications**

#### Publication and dissemination plan

The findings of this trial will inform the case for structured support to patients diagnosed with early-stage dementia and their carers. It is therefore planned to present findings to professionals who care for dementia; and to submit them for publication in high-impact medical journals and specialist mental health journals. If the trial is successful, the study team intends to develop a toolkit to inform commissioners, managers and practitioners in late 2018.

# Intention to publish date

31/03/2020

# Individual participant data (IPD) sharing plan

The datasets generated during and/or analysed during the current study are not expected to be made available

#### IPD sharing plan summary

Not expected to be made available

#### Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
<u>Protocol article</u>	protocol	10/10/2018	10/12/2020	Yes	No
Results article	results	19/10/2021	22/10/2021	Yes	No
HRA research summary			28/06/2023	No	No
Results article		30/06/2021	30/08/2023	Yes	No