

# Encouraging access for South Asians to timely dementia diagnosis

<b>Submission date</b> 21/07/2017	<b>Recruitment status</b> No longer recruiting	<input type="checkbox"/> Prospectively registered
		<input type="checkbox"/> Protocol
<b>Registration date</b> 31/07/2017	<b>Overall study status</b> Completed	<input type="checkbox"/> Statistical analysis plan
		<input checked="" type="checkbox"/> Results
<b>Last Edited</b> 12/07/2018	<b>Condition category</b> Mental and Behavioural Disorders	<input type="checkbox"/> Individual participant data

## Plain English summary of protocol

### Background and study aims

People from minority ethnic backgrounds tend to seek help later for dementia so their outcomes are likely to be worse. An educational programme has been designed to encourage South Asian people to seek help for dementia earlier. This involves providing people aged over 50 who are South Asian with information regarding dementia through their GPs. This programme needs to be tested to see how feasible it is to recruit and follow up participants in order to determine if the intervention is acceptable. The aim of this study is to evaluate the acceptability and feasibility of a programme that provides South Asian people with information about dementia to encourage them to seek help earlier.

### Who can participate?

South Asian adults aged 50 and older who have not been diagnosed with dementia.

### What does the study involve?

Potential participants are sent a letter from their GP informing them about the research study and advising them to get in touch with the researchers should they wish to take part. Once participants have indicated their interest in the study, they are sent the participant information sheet which has more detail about the study. Once they have had time to read the information sheet (at least 24 hours), the researcher contacts them to ask if they agree to take part. Participants are allocated to one of two groups. Those in the first group receive a letter and video about dementia. Those in the second group do not receive anything. Participants then are asked to make an appointment where they are asked questions about themselves, what they know about dementia and how they feel about getting help for memory problems. This same questionnaire is then repeated at a three month follow up appointment.

### What are the possible benefits and risks of participating?

There are no direct benefits with participating however participants receive high street vouchers to compensate for their time completing the questionnaires. There are no direct risks with participating however participants may find the questions about dementia distressing.

Where is the study run from?

This study is being run by University College London (UK) and takes place in eight health centres in the UK.

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

January 2013 to December 2017

Who is funding the study?

National Institute for Health Research (UK)

Who is the main contact?

Dr Naaheed Mukadam

n.mukadam@ucl.ac.uk

## Contact information

**Type(s)**

Public

**Contact name**

Dr Naaheed Mukadam

**ORCID ID**

<http://orcid.org/0000-0001-8635-9521>

**Contact details**

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## Additional identifiers

**EudraCT/CTIS number**

**IRAS number**

**ClinicalTrials.gov number**

**Secondary identifying numbers**

12 LO 1584

## Study information

**Scientific Title**

# Encouraging Access for South Asians to Timely Dementia Diagnosis: A pilot cluster randomised controlled trial

## Acronym

EAST-Dem

## Study objectives

It is feasible to recruit and follow up people for a pilot trial of an intervention to encourage help-seeking for dementia and the intervention will be acceptable.

## Ethics approval required

Old ethics approval format

## Ethics approval(s)

NRES Committee Fulham, 08/10/2012, ref: 12/LO/1584

## Study design

Pilot cluster randomised controlled trial

## Primary study design

Interventional

## Secondary study design

Cluster randomised trial

## Study setting(s)

GP practice

## Study type(s)

Other

## Participant information sheet

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

Dementia

## Interventions

Potential participants are sent a letter from their GP informing them about the research study and advising them to get in touch with the researchers should they wish to take part. Once participants have indicated their interest in the study, they are sent the participant information sheet which has more detail about the study. Once they have had time to read the information sheet (at least 24 hours), the researcher contacts them to ask if they agree to take part. Participants are then randomly allocated to one of two groups.

Intervention group: Participants are given a letter from their GP with an enclosed leaflet and DVD about dementia and getting help for memory symptoms. This is sent to participants once and they are then given complete an initial questionnaires and repeat the questionnaire again after three months.

Control group: Participants in this group receive no intervention and complete the same initial questionnaire and repeated questionnaire at three months.

## **Intervention Type**

Behavioural

## **Primary outcome measure**

1. Acceptability of intervention is measured using a Likert scale rating the intervention from completely unacceptable (1) to completely acceptable (5)
2. Feasibility of recruitment is measured using the proportion of people who consented to take part after initially expressing an interest in the study and follow-up is measured using the proportion of people who completed follow-up out of the initial sample

## **Secondary outcome measures**

1. Behavioural intention is measured using the APEND questionnaire, at the start of the study and approximately 3 months after the initial visit
2. Knowledge about dementia is measured using Dementia Knowledge Questionnaire at the start of the study and approximately 3 months after the initial visit

## **Overall study start date**

01/01/2013

## **Completion date**

31/12/2017

# **Eligibility**

## **Key inclusion criteria**

1. South Asian person registered to participating GP practice
2. Aged over 50
3. No known diagnosis of dementia

## **Participant type(s)**

Healthy volunteer

## **Age group**

Adult

## **Sex**

Both

## **Target number of participants**

80

## **Key exclusion criteria**

1. Diagnosis of dementia
2. Aged under 50
3. Not South Asian
4. No capacity to consent

**Date of first enrolment**

20/01/2016

**Date of final enrolment**

02/12/2016

## **Locations**

**Countries of recruitment**

England

United Kingdom

**Study participating centre****University College London**

Division of Psychiatry

Maple House

149 Tottenham Court Road

London

United Kingdom

W1T 7NF

**Study participating centre****Hampstead Group practice**

The Hampstead Group Practice

75 Fleet Road

London

United Kingdom

NW3 2QU

**Study participating centre****Prince of Wales Medical Centre**

52 Prince of Wales Road

London

United Kingdom

London NW5 3LN

**Study participating centre****Mathukia's Surgery**

281 Ilford Lane

Ilford

United Kingdom

IG1 2SF

**Study participating centre**  
**West Hampstead Medical Centre**  
9 Solent Road  
London  
United Kingdom  
NW6 1TP

**Study participating centre**  
**Dr Chawla Surgery**  
60 Victoria Road  
Barking  
United Kingdom  
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**Study participating centre**  
**King Edwards Medical Group**  
King Edward's Medical Centre  
1 King Edward's Road  
Barking  
United Kingdom  
IG11 7TB

**Study participating centre**  
**Abbey Medical Centre**  
85 Abbey Road  
London  
United Kingdom  
NW8 0AG

**Study participating centre**  
**Belsize Priory Medical Practice**  
208 Belsize Road  
London  
United Kingdom  
NW6 4DX

**Sponsor information**

**Organisation**

University College London

**Sponsor details**

Joint Research Office (part of the Research Support Centre)

UCL

1st Floor, Maple House – Suite B

149 Tottenham Court Road

London

England

United Kingdom

W1T 7DN

**Sponsor type**

University/education

**Website**

[www.ucl.ac.uk](http://www.ucl.ac.uk)

**ROR**

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

**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

Intent to publish our findings in a peer reviewed journal.

## Intention to publish date

12/12/2017

## Individual participant data (IPD) sharing plan

The datasets generated during and/or analysed during the current study are/will be available upon request from Naaheed Mukadam at [n.mukadam@ucl.ac.uk](mailto:n.mukadam@ucl.ac.uk).

## IPD sharing plan summary

Available on request

## Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
<a href="#">Results article</a>	results	01/05/2018		Yes	No