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Encouraging access for South Asians to timely dementia diagnosis

Submission date
21/07/2017

Recruitment status
No longer recruiting

Registration date
31/07/2017

Overall study status
Completed

Last Edited
12/07/2018

Condition category
Mental and Behavioural Disorders

[ ] Prospectively registered
[ ] Protocol
[ ] Statistical analysis plan
[X] Results
[ ] 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
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Contact information

Type(s)
Public

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Additional identifiers

Protocol serial number
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

Primary study design
Interventional

Study design
Pilot cluster randomised controlled trial

Study type(s)
Other

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(s)
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

Key secondary outcome(s)

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

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

Healthy volunteers allowed
No

Age group
Adult

Sex
All

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
United Kingdom

England

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

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

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.

IPD sharing plan summary
Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article	results	01/05/2018		Yes	No