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The south Asian dementia diagnosis pathway (ADAPT) online toolkit

Submission date
15/04/2021

Registration date
19/05/2021

Last Edited
25/09/2023

Recruitment status
No longer recruiting

Overall study status
Completed

Condition category
Nervous System Diseases

☐ Prospectively registered
☒ Protocol
☐ Statistical analysis plan
☐ Results
☐ Individual participant data
☐ Record updated in last year

Plain English summary of protocol
Background and study aims
Currently, there are about 25,000 people living with dementia in the UK who are from Black, Asian and other Minority Ethnic (or BAME) communities. People from south Asian (Pakistani, Indian and Bangladeshi) communities are the biggest minority ethnic group in the UK. They are more likely to be diagnosed with dementia at a later stage when their symptoms are much worse than are white British people. South Asians are less likely to be given medication or to receive recommended treatments for dementia and tend to be supported by community groups where staff may not be dementia trained.
The purpose of this study is to improve how dementia services meet the needs of south Asian people. We will do this by creating an online toolkit of culturally appropriate resources that health and social care professionals can use to enhance their local services.

Who can participate?
People from different south Asian communities who are affected by dementia, and NHS staff with experience in providing care for people affected by dementia from south Asian communities

What does the study involve?
In the first part of this project we will speak online or over the telephone to people from different south Asian communities who are affected by dementia to find out the best way to assess dementia and provide support. We will then look at how the NHS and community groups can work together effectively. We will create video clips of south Asian people talking about ‘best practice’ (e.g. how to work with interpreters). All of these resources will then be combined into an online toolkit. We will then share our findings by using social media and online ‘roadshows’. By making dementia services easier to use, people are diagnosed at an earlier stage and therefore have more support and treatment available to them.
Throughout the project we will be working closely with South Asian people affected by dementia including a number of ‘experts by experience’ from south Asian communities who will attend the steering group meetings and co-facilitate workshops and roadshows.

What are the possible benefits and risks of participating?
There may be indirect benefits to taking part in this study such as being part of research that we

hope will make a positive difference to the care and support provided to people living with dementia from South Asian communities. The project will give a seldom heard from group an opportunity to share their experiences. We do not see many risks in taking part in this study. In the unlikely event that during the discussion, participants become upset, then a member of the research team will provide immediate support and will offer a break if required.

Where is the study run from?
The University of the West of England (UK)

When is the study starting and how long is it expected to run for?
January 2021 to March 2022.

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

Who is the main contact?
Prof. Richard Cheston, Richard.cheston@uwe.ac.uk
Dr Sahdia Parveen, s.parveen27@bradford.ac.uk
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Additional identifiers

Integrated Research Application System (IRAS)
289226

Central Portfolio Management System (CPMS)
48458

Study information

Scientific Title
The south Asian Dementia diAgnosis PaThway (ADAPT) - an online toolkit of enhanced interventions

Acronym
ADAPT

Study objectives
Currently there are about 25,000 people living with dementia in the UK who are from Black, Asian and other Minority Ethnic (or BAME) communities. People from south Asian (Pakistani, Indian and Bangladeshi) communities are the biggest minority ethnic group in the UK. They are

more likely to be diagnosed with dementia at a later stage when their symptoms are much worse than are white British people. South Asians are less likely to be given medication or to receive recommended treatments for dementia and tend to be supported by community groups where staff may not be dementia trained.

The purpose of this study is to improve how dementia services meet the needs of south Asian people. The researchers will do this by creating an online toolkit of culturally appropriate resources that health and social care professionals can use to enhance their local services.

Ethics approval required

Old ethics approval format

Ethics approval(s)

Approved 12/02/2021, UWE Faculty of Health and Applied Sciences Ethics Committee (Glenside Campus, Blackberry Hill, BS16 1DD, UK; +44 (0)117 328 1170; Julie.Tonks@uwe.ac.uk), ref: HAS. 21.01.072

Study design

Non-randomized; Both; Design type: Process of Care, Management of Care, Qualitative

Primary study design

Other

Study type(s)

Treatment

Health condition(s) or problem(s) studied

Improving dementia services to meet the needs of south Asian people

Interventions

The purpose of the south Asian Dementia diAgnosis PaThway (ADAPT) study is to create an online toolkit of culturally appropriate assessments and interventions that support people from south Asian communities across the dementia care pathway. The researchers will do this through a series of linked work packages.

In the first work package, a rapid review will identify existing materials that enhance recognition of dementia symptoms in people from south Asian communities, enable assessment and promote support after diagnosis. The researchers will then establish the most appropriate elements of these materials that should be included in the toolkit by consulting with two groups of stakeholders; people living with dementia and their carers and staff and volunteers working in VCSO and NHS organisations. Given the ongoing pandemic situation, the researchers plan to carry out recruitment and data collection for this work package either through video or teleconferencing facilities. They envisage that they will not be able to hold any face to face meetings and workshops during this project and will therefore use online and telephone consultations instead.

In the second work package, the researchers will identify those factors that act as barriers or facilitators within statutory and voluntary sectors to the successful implementation of ADAPT. WP2 consists of two phases: phase 1 involves interviewing staff and volunteers working in organisations mainly in the Bristol and south-west to develop three vignettes that describe tensions that can arise in partnership working; in phase 2 these vignettes will be presented in online workshops (and where necessary through telephone calls) with similar staff and volunteers who will come largely from the Bradford and Wolverhampton areas. To avoid contamination, people who participate in phase 1 will not be eligible to take part in phase 2.

These two packages of work will enable us to identify the elements of the online toolkit. The third work package will then record video testimonies from south Asians with lived and professional experience of dementia. These will illustrate the key points of information that the researchers have identified, and these will also form part of the online web package, with shortened versions being used to disseminate key aspects of ADAPT through social media.

The ADAPT enhanced dementia care pathway will improve engagement of South Asians who are living with dementia and their families with dementia services provided by either the NHS or by VCSOs. Increased engagement will result in three key outcomes: greater access to NICE recommended treatments; increased rates of dementia diagnosis; and diagnosis occurring at an earlier stage of the illness.

Bringing together the ADAPT toolkit will enable us to move on, in subsequent research, to evaluate what aspects of the toolkit work best, for whom and in what contexts.

Intervention Type
Behavioural

Primary outcome(s)
WP1: Stakeholder responses to materials around dementia measured in a series of online workshops in June and July 2021
WP2: Stakeholder opinions as to the factors that act as barriers or facilitators to effective partnership working between statutory and voluntary sector organisations measured using interviews and onlione workshops in June and July 2021
We will analyse responses using thematic analysis.

Key secondary outcome(s))
There are no secondary outcome measures

Completion date
31/03/2022

Eligibility

Key inclusion criteria
Work package 1:
Either:
1. Someone living with a form of dementia (e.g. Alzheimer’s disease, vascular or mixed dementia) from a south Asian community (i.e. a family background from India, Afghanistan, Pakistan, Bangladesh, Nepal, Bhutan, the Maldives and Sri Lanka); or
2. Someone with experience of providing care to a family member or close friend who falls into category 1; or
3. Someone who works for a community-based organisation that provides care for people in category 1 or 2

Work package 2:
1. NHS staff with experience in providing care for people affected by dementia from south Asian communities

Work package 3:
1. People from a south Asian background either living with dementia themselves, providing care to a family member with dementia or working for an organisation that provides care to these communities

All participants will be required to have capacity to provide consent to take part in the research.

Participant type(s)
Patient

Healthy volunteers allowed
No

Age group
Adult

Sex
All

Total final enrolment
90

Key exclusion criteria
1. The main exclusion criteria for all three work packages is that the individual does not having capacity to provide consent to take part in the research
2. For WP1 and WP3 there are no further exclusion criteria
3. For WP2, we will recruit to two phases. Anyone who has participated in phase 1 will be excluded from phase 2

Date of first enrolment
02/03/2021

Date of final enrolment
30/11/2021

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
Dhek Bhal
43 Ducie Road

Bristol
United Kingdom
BS5 0AX

Study participating centre
Asian Elderly Day Centre
Summerhill Road
Bristol
United Kingdom
BS5 8HJ

Study participating centre
Touchstone Leeds
Touchstone House
2-4 Middleton Crescent
Leeds
United Kingdom
LS11 6JU

Study participating centre
Dementia Connect (Alzheimer's Society)
Castle Mill
Burnt Tree
Dudley
United Kingdom
DU4 7UF

Study participating centre
Positive Participation
Bob Jones Community Hub
Bromley Street
Wolverhampton
United Kingdom
WV2 3AS

Study participating centre
Memory Matters
Wednesfield Library
2 Well Lane

Wolverhampton
United Kingdom
WV11 1XT

Study participating centre
City of Wolverhampton Council
Carer Support Team
Civic Centre
St Peter's Square
Wolverhampton
United Kingdom
WV1 1SH

Sponsor information

Organisation
University of the West of England

ROR
https://ror.org/02nwg5t34

Funder(s)

Funder type
Government

Funder Name
NIHR Central Commissioning Facility (CCF); Grant Codes: NIHR200736

Funder Name
National Institute for Health Research (NIHR) (UK)

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 will be available upon request from Prof Richard Cheston (Richard.cheston@uwe.ac.uk) and/or Dr Sahdia Parveen (S. Parveen27@bradford.ac.uk), in the form of de-identified transcripts of interviews and workshops carried out during WP1 and WP2. This data will be available from 01/01/2022 until 31 /12/2026. Access to the data will be made depending on applicants being recognised researchers and having reasonable grounds for making such a request for the purposes of research.

IPD sharing plan summary

Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Protocol file	version V1	27/11/2020	19/05/2021	No	No
Study website	Study website	11/11/2025	11/11/2025	No	Yes