

The south Asian dementia diagnosis pathway (ADAPT) online toolkit

Submission date 15/04/2021	Recruitment status No longer recruiting	<input type="checkbox"/> Prospectively registered <input checked="" type="checkbox"/> Protocol
Registration date 19/05/2021	Overall study status Completed	<input type="checkbox"/> Statistical analysis plan <input type="checkbox"/> Results
Last Edited 25/09/2023	Condition category Nervous System Diseases	<input type="checkbox"/> Individual participant data <input type="checkbox"/> 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

Dr Emily Dodd, Emily3.Dodd@uwe.ac.uk

Study website

<https://raceequalityfoundation.org.uk/adapt/>

Contact information

Type(s)

Scientific

Contact name

Prof Richard Cheston

ORCID ID

<http://orcid.org/0000-0002-7466-3777>

Contact details

Dept of Health and Social Science

University of the West of England

Coldharbour Lane

Bristol

United Kingdom

BS16 1QY

+44 (0)117 3288927

richard.cheston@uwe.ac.uk

Type(s)

Scientific

Contact name

Dr Sahdia Parveen

ORCID ID

<http://orcid.org/0000-0002-5041-5306>

Contact details

Senior Research Fellow
The Centre for Applied Dementia Studies
University of Bradford
Bradford
United Kingdom
BD7 1DP
+44 (0)1274 236089
s.parveen27@bradford.ac.uk

Type(s)

Public

Contact name

Dr Emily Dodd

ORCID ID

<http://orcid.org/0000-0002-9505-257X>

Contact details

Trials Co-ordinator
Dept of Health and Social Science
University of the West of England
Coldharbour Lane
Bristol
United Kingdom
BS16 1QY
+44 (0)1173287496
Emily3.Dodd@uwe.ac.uk

Additional identifiers

EudraCT/CTIS number

Nil known

IRAS number

289226

ClinicalTrials.gov number

Nil known

Secondary identifying numbers

CPMS 48458, IRAS 289226

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

Secondary study design

Study setting(s)

Community

Study type(s)

Treatment

Participant information sheet

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

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 measure

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 online workshops in June and July 2021

We will analyse responses using thematic analysis.

Secondary outcome measures

There are no secondary outcome measures

Overall study start date

04/01/2021

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

Age group

Adult

Sex

Both

Target number of participants

Planned Sample Size: 96; UK Sample Size: 96

Total final enrolment

90

Key exclusion criteria

1. The main exclusion criteria for all three work packages is that the individual does not have 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

England

United Kingdom

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

Sponsor details

c/o Mrs Leigh Taylor
Senior Research Administrator
Research Administration, Northavon House
Bristol
England
United Kingdom

BS16 1QY
+44 (0)1173281170
leigh.taylor@uwe.ac.uk

Sponsor type

University/education

Website

<http://www.uwe.ac.uk/>

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

Publication and dissemination plan

The researchers intend to publish the findings of this study in high impact peer-reviewed academic journal. They will also disseminate via practitioner journals, blogs and conferences. They will submit all manuscripts within 1 year after the study end.

Intention to publish date

01/09/2024

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