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Better conversations with primary progressive aphasia and other rare dementias: speech and language therapy to keep families together

Submission date
10/09/2025

Recruitment status
Recruiting

Registration date
19/09/2025

Overall study status
Ongoing

Last Edited
10/08/2026

Condition category
Mental and Behavioural Disorders

[_] Prospectively registered
[X] Protocol
[_] Statistical analysis plan
[_] Results
[_] Individual participant data
[X] Record updated in last year

Plain English summary of protocol

Background and study aims

The number of people living with dementia is estimated at 850,000 in the UK and is set to triple by 2050. Of these, several thousand have primary progressive aphasia (PPA): a group of early-onset language-led dementias. People with PPA experience a deterioration in communication that affects their employment, their social lives and relationships, often leading to depression and social isolation for them and their families. Many people with other rare dementias also experience these devastating difficulties. Speech and language therapy (SLT) is the only available intervention that addresses these issues. Yet, this is an under-researched area. Consequently, SLT services are often poorly commissioned and difficult to access. Therefore, work is urgently required to develop evidence-based language and communication interventions for PPA and other rare dementias.

People with PPA and their family members have highlighted a need for interventions to help them feel more skilled in conversations. In previous work undertaken by the Chief Investigator, during her NIHR-funded PhD, a coproduced intervention called Better Conversations with PPA (BCPPA) was piloted across 11 NHS trusts with 18 people with PPA and their family members.

The BCPPA program aims to improve communication, self-efficacy, well-being and quality of life of those living with dementia and their families. The intervention currently comprises four sessions where the SLT supports the dyad to identify facilitators and barriers to conversation through the use of video feedback. Together, the SLT and the ‘dyad’, or person with dementia and their communication partner (CP), practice strategies to improve communication.

The research undertaken by the Chief Investigator showed that speech and language therapists could deliver BCPPA in the NHS, and that people with PPA and their families were positive about it. This work raised questions about when, along a person's disease journey, this intervention should be delivered, how to best measure the effectiveness of the intervention and whether BCPPA might be acceptable and useful to people with other types of dementia. Finally, given that in the UK two-thirds of the cost of dementia is borne by family carers, we also had questions about the possible economic implications of BCPPA. Consequently, the current protocol

describes a mixed-methods process evaluation study in the form of a randomised controlled cross-over pilot feasibility study to address the following research questions:

Objective 1: What is the optimal schedule and dosage of BCPPA versus treatment as usual?

Objective 2: What are the selection criteria for the BCPPA intervention versus treatment as usual?

Objective 3: Is remote delivery of BCPPA acceptable to people with PPA and other dementias?

Objective 4:What is the best way to measure the intervention for a future fully powered effectiveness study?

Objective 5: What is the most appropriate perspective of analysis and way of measuring costs and outcomes in a future cost-effectiveness analysis of BCPPA versus usual care?

Who can participate?
The BCPPA program will be piloted with 36 dyads, recruited from the NHS. Potential participants will be screened to make sure they have a diagnosis of dementia, can participate online in the therapy and have a willing and consenting partner.

What does the study involve?
The study will employ a randomised controlled, crossover waiting list design. Having given informed consent, including to being video recorded, participants will then be randomly allocated to receive BCPPA immediately for 4-6 weeks once a week on a video conferencing platform (Zoom), or to a waitlist control. Those randomised to the waitlist then receive the BCPPA intervention following the waiting period. A speech and language therapist will deliver the BCPPA intervention, aiming to improve conversations.

What are the possible risks and benefits of participating?
We think that the main risks are that some people might find the testing for the study tiring or upsetting, but that they may find the study improves their conversations and communication.

Where is the study run from?
University College London (UCL), and will be hosted at the UCL Hospital, UK.

When is the study starting and how long is it expected to run for?
December 2024 to January 2030

Who is funding the study?
The study is funded by an NIHR fellowship awarded to the lead investigator, Dr Anna Volkmer.

Who is the main contact?
Dr Anna Volkmer a.volkmer.15@ucl.ac.uk

Contact information

Type(s)
Public, Scientific, Principal investigator

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Additional identifiers

Integrated Research Application System (IRAS)
341322

Central Portfolio Management System (CPMS)
65106

Protocol serial number
Protocol number 168086

Study information

Scientific Title
The 'Better Conversations with Primary Progressive Aphasia and other rare dementias (BCPPA)' telehealth communication partner training program: A clinical and health economics NHS embedded randomised controlled feasibility (embedded implementation) study protocol

Acronym
BCPPA with rare dementias

Study objectives
To conduct a mixed-methods process evaluation, in the form of an NHS-based randomised waitlist-controlled feasibility study, comparing BCPPA to waiting list control, for people with PPA and other rare dementias and their communication partners.

Implementation:
Objective 1: What is the optimal schedule and dosage of BCPPA versus treatment as usual?

Feasibility:
Objective 2: What are the selection criteria for the BCPPA intervention versus a waitlist control study?
Objective 3: Is remote delivery of BCPPA acceptable to people with PPA and other dementias?
Objective 4: Evaluation of intervention to establish a sample size calculation for a future fully powered study
Objective 5: What is the most appropriate perspective of analysis and way of measuring costs and outcomes in a future definitive cost-effectiveness analysis of BCPPA versus usual care?

Ethics approval required
Ethics approval required

Ethics approval(s)
Approved 23/12/2024, HRA and Health and Care Research Wales (HCRW) (Ground Floor, Skipton House, 80 London Road, London, SE1 6LH, United Kingdom; -; approvals@hra.nhs.uk), ref: 24/NI/0123

Primary study design
Interventional

Study design
Mixed-methods process evaluation randomised waitlist-controlled feasibility study

Study type(s)
Treatment

Health condition(s) or problem(s) studied
People with dementia and their families

Interventions
Design:
This pilot feasibility trial will be a randomised waitlist-controlled trial design. Comparisons will be made between groups on pre- and post-treatment measures, comparing the scores pre- and post the BCPPA program, with pre- and post the waitlist control group. Maintenance will be measured at the 3-month follow-up.

Interventions will be delivered by either:
A research assistant (RA) - a highly specialist, HCPC registered speech and language therapist (SLT) with experience working with people with aphasia, PPA, rare dementias and AD; the majority (over 80%) of intervention will be delivered by the RA.

or a local collaborator (also a specialist, experienced HCPC registered SLT), trained to deliver the interventions by the RA or principal investigator.

Recruitment:
The RA, or a local collaborator (specialist nurse, or SLT) at each site, will recruit and screen potential participants with dementia and their communication partners. The only data to be collected at this stage is names, preferred contact details and an indication that they meet the inclusion and exclusion criteria. This will be shared with the Research Team via secure NHS email, as per the usual process for referring people across NHS trusts

The RA or participating local SLT collaborator involved in delivering the study will consent participants with dementia and their communication partners. Local SLT collaborators will have received full training by the Chief Investigator in how to support a person with dementia to understand the commitments required and information around the study, and advice on how to assist someone to make an informed decision to consent. This will supplement local mandatory Mental Capacity Act training that all local collaborators will have completed.

The RA and all local collaborators will be supported in the recruitment of potential participants, with weekly or fortnightly meetings with the CI, where potential participants will be anonymously discussed on a case-by-case basis to determine eligibility.

Research sites:
Cognitive Disorders Clinic, University College London Hospital NHS Foundation Trust, London, UK (UCLH)
Speech and language therapy service, Leicestershire Partnership NHS Foundation Trust, Prince Philip House, Malabar Road, Leicester, LE1 2NZ

Local memory disorders clinic and speech and language therapy managers (UCLH and Leicestershire) have agreed in principle that the specialist nurse or SLT at the following sites will recruit participants and obtain consent.

All health care professionals involved in referring people with dementia to the SLT will be asked to participate in semi-structured interviews, informed by Implementation Theory, to capture perceived barriers and facilitators for future implementation (see draft Topic Guide in appendices).

Sample size:
Based on pilot study findings and NHS site referral rates, we plan to recruit 36 people with dementia and their relevant communication partner (usually a spouse, relative or friend), i.e. 72 in total.

Randomisation:
Each participant will be assigned a participant ID upon consenting to participate in the study. Randomisation will occur after the participant has completed the baseline and pre-intervention outcome measures, using an online random number generator, by the study Cl, who is external to the research team delivering the intervention.

Outcome measures:
Outcome measures will be collected at 4 or 5 time points, depending on randomisation. All participants will complete baseline measures on two occasions before randomisation. Participants randomised to receive the intervention immediately will complete measures post-intervention and at 3-month follow-up. Participants randomised to the waitlist control group will complete post waitlist control, post intervention, and at 3-month follow-up.

Participants will complete baseline measures face-to-face in an outpatient setting or their own home. The combined time for completing the measures should not exceed 1.5 hours, including greetings, pleasantries, rapport building and switching between tests. Baseline measures will be administered by the RA; all post-intervention, post waitlist and 3-month follow-up measures will be administered by a junior researcher (a speech and language therapy student with skills in the assessment of people with PPA and AD) but crucially masked to treatment group allocation (BCPPA immediate or waitlist control). Junior researchers will be asked to keep a log of whether they believe they have been unmasked or not, and will receive guidance and training from the RA on how to remain masked.

BCPPA Intervention:
The BCPPA program will consist of six 1-hour sessions over 6 weeks. People with PPA and their CPs will both attend, and sessions will be facilitated by the RA or local collaborator SLT, via the teleconferencing platform Zoom. Set-up and testing of the teleconferencing platform will already have been completed by the RA or collaborator SLT. BCPPA is based on the techniques

outlined in the Better Conversations with Aphasia (BCA) program (Beeke et al, 2013). Video samples are made by the participants (to ensure naturalness) at the start of the program, so that the SLT can assess the dyads' difficulties before commencing the program. First, the SLT provides the person with PPA and their CP information and education on conversation. The SLT then supports the dyad to analyse the video sample of their own conversation to identify points that facilitate or are a barrier to communication. Consequently, participants are supported to set goals using the Goal Attainment Scales (Turner-Stokes, 2003) to identify target communication strategies which they practise using through role play and home challenge tasks (a summary providing an overview of the BCPPA intervention, before refinement for online delivery, is attached as an appendix).

Waitlist Control:
Participants randomised to the waitlist control will receive no speech and language therapy for the duration of this period.

For the entirety of their participation in the study, participants assigned to both groups will receive usual health care provision (anticipated to include neurology, GP reviews, and allied health input such as physiotherapy). However, this will exclude any other SLT intervention until the 3-month follow-up appointment. Following this period, participants will be able to resume all aspects of SLT provision without further interruption.

Schedule of participant activity in study:

Week 1: All participants - Consent form, Demographic Information, Outcome measures, Video recording of conversation x1
Week 2: All participants - Outcome measures, Collect video-recorded conversations made by participants in the week between visits
Week 3-8: All participants - BCPPA OR no treatment waitlist, baseline measures (Time 2) and randomisation to relevant group
Week 9: All participants - Outcome measures, Video recording of conversation x1, ONLY for post-intervention- semi-structured interview
Week 10: All participants - Collect video-recorded conversations made by participants in the week between visits
Weeks 11-16: Waitlist participants to do the BCPPA intervention
Week 17: Waitlist participants who have just completed BCPPA Outcome measures, Post-intervention- semi-structured interview, Video recording of conversation x1
Week 18: Waitlist participants - Collect video-recorded conversations made by participants in the week between visits
Week 22: BCPPA first participants - Final 3-month post-intervention outcome measures Video recording of conversation x1
Week 23: BCPPA first participants - Collect video-recorded conversations made by participants in the week between visits
Week 30: Waitlist participants - Final 3-month post-intervention outcome measures Video recording of conversation x1
Week 31: Waitlist participants - Collect video-recorded conversations made by participants in the week between visits

Intervention Type
Behavioural

Primary outcome(s)

Communication confidence measured using the Communication Confidence Rating Scale for Aphasia (CCRSA), and communication participation using the Communication Participation Item Bank (CPIB). Participants are measured twice at baseline, pre-randomisation, once post-intervention/waiting list control period and again at 3 months after the intervention.

Key secondary outcome(s)
The following secondary outcome measures are completed twice at baseline, pre-randomisation, once post-intervention/waiting list control period and again at 3 months after the intervention:
1. Language skills and discourse are measured using the Comprehensive Aphasia Test (CAT) and a personal narrative
2. Conversation is measured using conversation samples. At each time point, participants will make four 10-15-minute video recordings of natural conversation. These will be assessed using the Kagan MSC-D/MPC-D Scale.
3. Participation will be measured using the American Speech-Language-Hearing Association Functional Assessment of Communication Skills for Adults (ASHA FACS)
4. Relationship will be measured using the Quality of caregiver-patient relationship
5. Health economics measures include the EQ5-5D-5L+C, the Investigating Choice Experiments for the Preferences of Older People - CAPability index (ICECAP-O) and the Resource utilisation in dementia (RUD) questionnaire

Completion date
01/01/2030

Eligibility

Key inclusion criteria
Participants with dementia will be invited to participate in the study if they fulfil the following criteria:
1. Have a diagnosis or possible diagnosis of dementia (e.g. PPA, FTD, PCA, AD), as identified by a specialist diagnostic dementia service (informed by case history, neurological examination, brain imaging and appropriate psychometric testing if required) and in line with current diagnostic criteria.
2. Have the ability to communicate and understand communication to participate remotely in the BCPPA program
3. Able to see and hear well enough to participate remotely in the BCPPA program
4. Are functionally able to engage in a remotely delivered BCPPA program (i.e. able to maintain some concentration and remain in a 60–90-minute session with support, minimal challenging behaviour that would be unlikely to cause disruption)
5. English as their language of daily use
6. Have a communication partner (CP- family member or friend) who can and consents to participating in the project
7. To be confirmed by the RA or local SLT collaborator at the consent appointment: Have access to the internet at home with a minimum speed of 3.8Mbps download and 3Mbps upload to achieve 1080p HD video for group conference calling. (NB ideally within the 10 to 25 Mbps download speed range and at least 5 Mbps upload speed for best results). A home visit or remote internet speed test and advice session by the RA (or local SLT collaborator, where appropriate) will occur to test and optimise speeds (e.g. by troubleshooting, using cabling, cache flushing, etc).
8. To be confirmed by the RA or local SLT collaborator at the consent appointment: Be able to use a Mac laptop computer (which will be loaned by the research team) with support from either the CP or person with dementia (either of whom may be the most technology literate) to use the

teleconferencing platform, Zoom. NB: Computer use and teleconferencing platform access will also be facilitated in pre-treatment set-up sessions.

Communication partner:
Having identified a potential participant with dementia who fulfils the inclusion criteria outlined above, their communication partners will also be invited to participate in the study in line with the following criteria:
1. They have been identified by the participant with dementia as a communication partner
2. They can attend the appointments and consent to participating in the study
3. Can see and hear well enough to participate remotely in the BCPPA program
4. English as their language of daily use

Participant type(s)
Patient

Healthy volunteers allowed
No

Age group
Mixed

Lower age limit
18 Years

Upper age limit
110 Years

Sex
All

Total final enrolment
0

Key exclusion criteria
Participants with dementia and communication partners:

People (both participants with dementia and their communication partners) will be excluded from participation in the pilot if they:
1. Do not have the capacity to consent
2. Have a history of brain lesions or major head trauma
3. Have a major physical illness or disability which could impact participation
4. Present with a major psychiatric diagnosis
5. Present with prominent behavioural disturbance
6. Present with prominent episodic memory, visual memory or visuoperceptual impairments which would preclude access to telehealth
7. Do not have functioning, reliable internet access at speeds over 3.8Mbps download and 3MBps upload.
8. Are unable to demonstrate as a dyad that they can use a Mac laptop computer to access video conferencing (via Zoom)

Additionally, communication partners will be excluded if they have a diagnosis of dementia themselves. As per routine practice, the researchers will not have access to the communication partner's medical record and judgments about inclusion and exclusion will be made based on what potential communication partner participants report to the research team.

Date of first enrolment
12/02/2025

Date of final enrolment
31/07/2027

Locations

Countries of recruitment
United Kingdom

England

Wales

Study participating centre
University College London Hospitals NHS Foundation Trust
250 Euston Road
London
England
NW1 2PG

Sponsor information

Organisation
University College Hospital

ROR
https://ror.org/00wrevg56

Funder(s)

Funder type
Government

Funder Name

National Institute for Health and Care 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 will be available on request from a.volkmer.15@ucl.ac.uk.
• The type of data that will be shared - outcome data (discourse and language measures, patient-reported outcomes related to confidence, participation and quality of life and video data - if appropriate), anonymised demographic information
• Timing for availability - after trial publication
• Whether consent from participants was required and obtained - this was required and obtained
• Comments on data anonymization - video recordings will be blurred for anonymity
• Any ethical or legal restrictions - only available to researchers in England and Wales

IPD sharing plan summary
Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Protocol article		07/08/2026	10/08/2026	Yes	No
Participant information sheet	version 3.0	18/12/2024	11/09/2025	No	Yes