

## Participant Information Sheet

Better Conversations with Primary Progressive Aphasia and other rare dementias (BCPPA)



This project has been approved by the NHS Health Research Authority IRAS ID 341322

### Invitation to participate in research

You have been invited to participate in this study because you have a diagnosis of **primary progressive aphasia** or other **type of dementia**.

### Before you accept it is important to understand:

- **Who** is doing the research?
- **Why** is the research being done?
- **What** will it involve?
- **You can choose** if you do or do not want to do the research.
- You can **talk about this with family and friends**.
- You can **ask questions** at any time.

## Who is doing the research?



The research is being done from **University College London**.



The **main researcher on this project** is: Anna Volkmer



You can contact her on

**07597 407 187** or

[a.volkmer.15@ucl.ac.uk](mailto:a.volkmer.15@ucl.ac.uk)

**NHS**  
**National Institute for  
Health Research**



The **National Institute for Health Research** is **paying** for this research – this includes paying you back for any traveling you might have to do.

## Why is the research being done?



Speech and language therapists provide **therapy** for people with **communication difficulties and their families.**



We **don't know** enough about whether it helps people with **primary progressive aphasia** or other rare dementias.

This research will help us **learn more.**



We have developed a **therapy treatment** called **Better Conversations with Primary Progressive Aphasia.**



We want to know:

- If it works on-line on a video call (Zoom)
- If people with different types of dementia like it
- how many sessions we need

## What will it involve?



We want **36 pairs** to take part.

We want to **compare** Better Conversations with **no treatment**



**Half** the people will have the Better Conversations **treatment for 6 weeks.**

**Half** the people will wait for 6 weeks and have **no treatment.** This is a bit like being on a **waiting list.** Then they will have the Better Conversations **treatment for 6 weeks.**

Better Conversations with PPA



Wait for treatment

If you agree to take part **you will be randomly** assigned to either:

- 1) Better Conversations
- OR
- 2) Waiting for treatment.

## What will I have to do?

### The tests:



A speech and language therapist researcher will **test your talking and understanding**. They will ask **you and your partner** how you both feel about talking and the impact that the dementia has on your lives. This will take about 90 minutes. You will both do **these tests**:

- Twice before treatment
- after waiting for treatment (if you wait)
- immediately after treatment
- 3 months after treatment



You will be **video recorded 4 times** having a conversation with your partner. The speech and language therapist will help you make 1 video, you will make 3 videos at home on your own. **We will train you to make a video using an iPad**. We will collect the videos from your home. You will make videos:

- Once before treatment,
- after waiting for treatment,
- immediately after treatment
- 3 months after treatment

### Better Conversations with PPA therapy treatment



You will have up to six, one-hour therapy sessions remotely on zoom to **watch the videos** with the speech and language therapist. The speech and language therapist will help you see the good strategies, and things that are not working well. You and your partner will **practice** how to make **conversation easier**. We will video record all the therapy to make sure we are doing it the same with everyone.

### While you are waiting for treatment or more tests



You will have **no speech and language therapy** while **you are waiting**. You will get all your other NHS care as normal.

## What will we do with information we collect?



We will collect information about **you**, your **contact details** and when you were diagnosed. We will also ask you what other **languages** you speak, your previous **occupation** and other **medical conditions** you might have. **After** you have done the Better Conversations therapy, **we will also ask you some questions about what you thought of the intervention.** This will happen during the visit to your home when we repeat the tests.



The consent form with your name on it will be kept in a **locked** filing cabinet at UCL for **10 years**. All other data will be **anonymised** and stored on a UCL computer database called the Data Safe Haven.



Videos will be **stored safely** on a UCL computer database called the Data Safe Haven.

**After the study** is finished you can go back to your **usual speech and language therapy.**

## How do I decide?



**You can choose** if you want to do the research or not.

To be in the study **both of you** must agree **to do it together**. You can **talk about this** with **family and friends**.



**You can stop** being in the research at any time. If you stop you do not have to give a reason and **you will still get your normal care**. If one of you pulls out, you will both have to.



If you stop **your data will still be included in the study**.



We will **only include you in the study if you are able to make a decision**.

If you **lose the ability to make a decision** during the study, **we will ask your family member or friend** what they think. We will ask them for their opinion and/or advice as to what your wishes might be.

## How will we contact you?



If you do decide to be in the study we will **contact you by telephone and/or email or letter** to arrange the first meeting to complete the tests and make videos.

This **meeting will be in person**. We can visit you at your home or see you in the hospital where you are receiving your treatment. You can choose.

The **treatment will be once a week on Zoom for six weeks**. We will then see you in person again to do the tests and make videos.

If you have been initially randomised to have no treatment (or to wait for treatment), you will then have the treatment on zoom and be seen in person again for tests and make videos .

**Three months after the treatment we will visit you again** to do the tests and make videos.

If you would like **we can let your doctor know** that you are taking part. If you tell us that you or someone else are **at risk of harm we will need to speak to other people** about this to keep everyone safe.



## Using videos to do more research



You can choose if other researchers look at the videos to do more research. They **will** be able to see your faces. You and your partner will both need to consent to the same thing:



If you both decide to share the videos, we will store them, as planned on the encrypted UCL Data Safe Haven - where the research team can decide who uses the videos. Only researchers that we decide will do more research with your videos. **10 years after the study ends**, they will be destroyed.



In addition, you can both also choose to store them in the Human Communication Audio Visual Archive (CAVA) at UCL Library. **The videos will be stored for as long as the Library exists.** Future researchers from outside the research team can access them if they sign a contract. They must respect your confidentiality, rights and dignity and use the videos responsibly.

## Using videos at conferences and for teaching



You can choose if you would like the research team to use clips from your videos for teaching or at conferences. You and your partner will both need to consent to for us to share the videos.



If you tell us you are happy for the research team to use videos of you for teaching or conferences we will check with you both again at the end of the study which videos we can or cannot use.

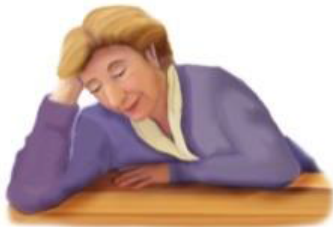


When we show your **videos in teaching or at conferences, we will blur the videos** so people cannot see your face.

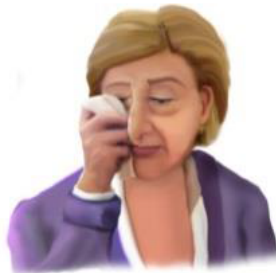
## What might be difficult about taking part?



You may find **it won't help you.**



You may find it **tiring.**



You may find it **upsetting.**



Therapy will take up to **6 weeks of your time.** The time in the study will take up to **31 weeks**

## What might be good about taking part?



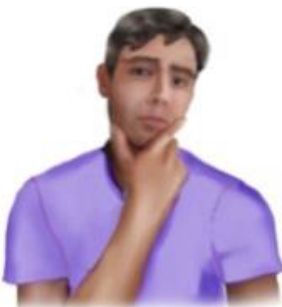
You may find it **helps** you.

Other people have found it:

- makes conversations easier
- improves things with their partners or family members
- makes them feel more confident



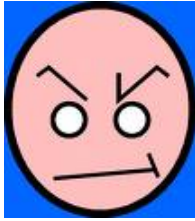
You may **enjoy** taking part.



You may find it **interesting**.



The results may **help other people** in the future.



If you need to make a **complaint** or you think you were **harmed please contact:**



1. The main researcher,  
Anna Volkmer,  
Chandler House  
2 Wakefield Street  
London WC1N 1PF

**07597 407 187**

Email: [a.volkmer.15@ucl.ac.uk](mailto:a.volkmer.15@ucl.ac.uk)

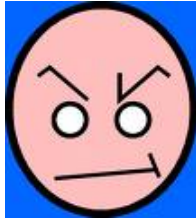
Or



2. Spenser Crouch Legal Services,  
Finance & Business Affairs,  
UCL 6th floor,  
1-19 Torrington Place London WC1E 7HB

Tel: 0203 108 8764

Email: [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)



# PALS



If you are **still unhappy**, make a **formal complaint** by **writing** to the NHS Trust that is looking after you.

## UCLH Patient Advice & Liaison Service (PALS)

**Address:** PALS

Ground Floor Atrium  
University College Hospital  
235 Euston Road  
London NW1 2BU

**Telephone** (main hospital):  
02034473042

**Telephone** (NHNN): 02034483237

You can also contact the UCLH Patient Advice and Liaison Service on **02034483237/02034473042** (as appropriate see above) or email [Uclh.pals@nhs.net](mailto:Uclh.pals@nhs.net)

The University has **insurance**.

## Data Protection Privacy Notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data is: 'public task' and 'research purposes' will be the lawful basis for processing special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data, you provide we will undertake this and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)