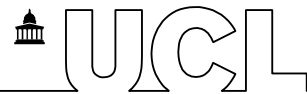


Evaluating a self-managed sentence therapy for people with aphasia
Information Sheet for participants with aphasia – Approved

UCL LANGUAGE AND COGNITION

Division of Psychology and Language Sciences



Information Sheet for Participants in Research Studies

You will be given a copy of this information sheet.

Project: Evaluating a self-managed sentence therapy for people with aphasia

This study has been approved by the UCL Language and Cognition Department Ethics Committee; Project ID Number: LCD-2022-18

We would like to **invite you to take part in a research project.**

Who we are:



Dr Claudia Bruns

✉ c.bruns@ucl.ac.uk

☎ 020 7679 4292



Prof Rosemary Varley

✉ rosemary.varley@ucl.ac.uk

☎ 020 7679 4234



Fern Rodgers

✉ f.rodgers@ucl.ac.uk

☎ 020 7679 5785



Kerry Dathan

✉ kerry.corley.16@ucl.ac.uk

☎ 020 3108 5381

Work address:

Division of Psychology and Language Sciences
University College London (UCL)
Chandler House
2 Wakefield Street
London WC1N 1PF

Thank you for reading this.

What you need to know

You are being invited to take part in a research study.

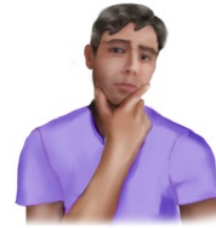
This research **includes therapy**.

Before you decide to take part, it is important for you to understand **why** the research is being done and **what** you have to do.

Please **take time to read** the information carefully and discuss it with your family and friends.

Ask if anything is not clear or if you want **more information**.

Take your time to decide if you wish to take part.



Why are we doing this research?

Some people find listening to and talking in **sentences** difficult after a **stroke**.

We want to find out if a **new, self-managed therapy** can **help** people with difficulties understanding and producing sentences.



Why me?

You have **difficulties understanding sentences** and **speaking** following a **stroke**.



Do I have to take part?

No. You can decide.

If you want to take part, you can **keep** this information sheet.

A researcher will invite you to **Chandler House** at UCL in **Bloomsbury**.

You will need to **sign a consent form** to show you are happy to take part.

Even if you decide to take part, you can **stop** the study at **any time** and without giving a reason. If you withdraw from the study, we will ask you if you want the information that has been collected to be destroyed.

If you say **no**, this will **not** influence your relationship with UCL.

If you say **no**, you will still get your **normal help and services**.



What will happen to me if I take part?

There will be **three stages** in the study.

Stage 1

You will **come to UCL Chandler House** for **two** meetings.

You do some **language and thinking tests** so we can measure your language and other abilities **before the therapy**.

There will be **two meetings**, each taking **60-90 minutes**.

You can take a **break** whenever you need one.

Stage 2

If the therapy and research procedures are suitable for you, we will **lend** you a **tablet computer**.

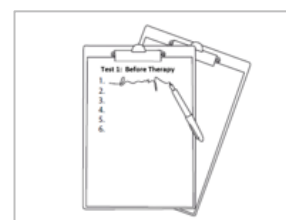
The therapy will be done **at home** using the **tablet computer**.

We will take the tablet computer back at the end of the study. A researcher will set up the tablet computer.

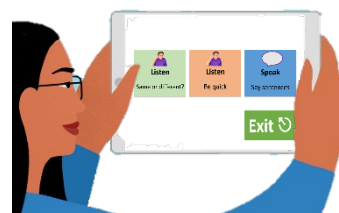
You will do the **therapy** at home for **4 weeks**.

You will need to have **access to the internet at home** to practice therapy tasks via the app.

Stage 1



Stage 2



Stage 3

After the **therapy** has **finished** there will be **two more meetings** to see if your listening or speaking has changed. These will take **60-90 minutes**.

We **repeat some of the tasks** from **Stage 1**. This will tell us if the therapy is effective and useful for other people with strokes.

You will **return the tablet computer**.

We will also **ask** some questions about your opinion on the therapy app.

We will pay you **£15** towards your expenses for **each meeting at Chandler House**.

After therapy, we will **ask a family member or friend** some questions about you using the therapy at home, such as how much they needed to help you to use the app. This is **optional** so they don't have to do this. **You can still take part** if no family member is available.

Stage 3



Stage 1: Measuring language before therapy

You will come to **UCL Chandler House** for a meeting that takes around **60-90 minutes**.

We will ask **questions** about your **stroke** and your **abilities**.

You do some **language and thinking tests**

You might **name or describe pictures**, and **point at pictures**.

We **ask you some questions** about your **interests**.

Your speech will be **audio** recorded.

This will allow us to understand the difficulties you have before therapy.

When there is space available, you will be invited to attend your **next** meeting. This takes around **60-90 minutes**.

We will measure your language **again** to find out if there is any **change** in your speaking **before the therapy starts**.



Stage 2: Therapy

The **therapy** has three tasks.

You will **listen** to and **say** sentences using a **tablet computer** that you will **borrow** from us.

A researcher will help you learn how to use the computer.

You will **use the computer at home**.

We encourage you to do the therapy for **at least an hour** a day for **4 weeks**. You can do short sessions, for example:

2 x 30-minute sessions per day, **or**

3 x 20-minute sessions.

We will **monitor your progress every week**.

You can **ask us for help** through the app.

1) You **listen** to pairs of **sentences** of increasing length.

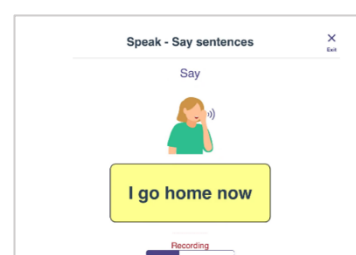
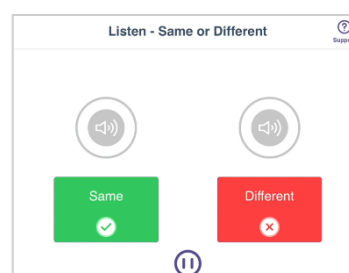
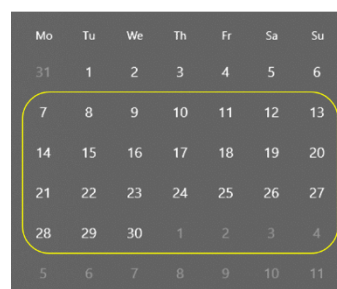
You decide if the pairs were the **same** or **different**.






2) You **listen** to **words** and **sentences**.

You will press a button, as quickly as you can, when you hear a certain word.

3) You practice **saying** short sentences.

The computer will **record** your speech.



<p>You can stop the treatment at any time, without having to give a reason. We will arrange for the computer to be taken away.</p>	
<p>Stage 3: Measuring language after therapy</p> <p>At the end of the therapy, and again 8 weeks later, we will ask you to repeat the tests to see if your understanding of sentences and speaking have changed. Each of these two meetings takes around 60-90 minutes.</p> <p>You can tell us what you thought about the therapy in a questionnaire.</p> <p>For some tests, we can tell you if your scores have changed (if you want to know this).</p> <p>We will take back the tablet computer.</p> <p>No information about you will be kept on the tablet computer.</p>	 
<p>What are the alternatives for treatment?</p> <p>We are only offering this experimental intervention. Your speech and language therapist or GP might be able to advise you about alternative forms of therapy.</p>	
<p>What are the side effects of any treatment received when taking part?</p> <p>There are no known side effects associated with the intervention tasks.</p>	

What are the possible disadvantages and risks of taking part?

It will **take up your time**.

You may find it **tiring** or **distressing**.

You may become **frustrated** if you feel you are not improving or if there are technical problems.

However, **we will provide you with support** throughout the study through **phone and video calls**.

This is a new and experimental intervention.

The **intervention might not help you**.

If it does not help you, things will stay the same as they are now.



What are the possible benefits of taking part?

You may **enjoy** taking part.

You may be **helped** by the therapy.

You will **help us learn more** about what could be good about the therapy.



What happens when the research study stops?

The **tablet computer** and the **therapy** will **not be available** after the research study finishes.

However, if the intervention is successful, we hope that similar therapy programs may be available **in the future**.



What information will be collected?

We will ask you some **questions** about the date of your stroke and what you feel about your current abilities.

We will collect information on your **listening and reading words and sentences**, and processing information.

We will make **audio recordings** of your speech when doing tests and using the app.



Who will see the results about me?

Only **members of the researcher team** will see the **information** about you and listen to the recordings of your speech.



We will **ask you if you agree** to share your information with your **speech and language therapist**.

We will **tell other researchers** (in the UK and across the world) about the results.

We hope to **publish** the **results** in **journals** and **presentations** at **conferences**.

When we **present** the results of this study, we will **never use** your real **name**.

No one **outside the study** will know **who you are** from the results.

The results of the study may be useful for **other researchers**. For example, evidence from different



treatment studies can be combined to see what the most effective form of therapy is.

We will **ask you if you agree** to your anonymised scores being **shared** with other researchers.

Again, no one will **know who you are** from this.

If you prefer to have your **audio recordings destroyed after analysis is finished**, you can let us know.



After analysis:



COVID-19

We have safety procedures to **reduce risk** of COVID-19 infection.

For example, we may do a short **health screening** before a meeting at Chandler House.

We provide **hand sanitiser**. You can clean your hands regularly.

All equipment will be **disinfected** before and after your visit.

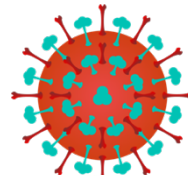
The researcher will maintain **social distance** where possible. Sometimes they will be close to you so they can set up equipment.

You must let us know **if you test positive** for COVID-19 **within 1 week of your visit to UCL**.

We are following **UCL and government guidelines**.

However, we **cannot** completely remove the **risk**.

If you travel to and from UCL on **public transport**,



there is a **risk of COVID-19** through exposure to other **passengers**.

It is **your decision** whether to take part.

What if something goes wrong?

If you **take part** in the research and **if you think** you were **harmed** there are **people to talk to**.

If you are harmed by taking part in this project, there are no special compensation arrangements.

If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it.

If you wish to **complain**, or have any **concerns** about any aspect of the way you have been approached or treated during the course of this study, you can

contact Prof Rosemary Varley

Department of Language & Cognition
2 Wakefield Street, London WC1N 1PF
rosemary.varley@ucl.ac.uk

Tel. 020 7679 4234

If you do **not** receive a satisfactory response, you can

contact Dr Fiona Kyle

Chair of Ethics Committee,
Language & Cognition
f.kyle@ucl.ac.uk

Tel. **020 7679 8692**



Information that has been provided in confidence and **personal information will not be used or shared without your consent.**

Anonymised data will not be shared with other researchers **without your consent.**



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

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



<p>Who has approved the study?</p> <p>The study has been approved by the UCL Language and Cognition Department Ethics Committee. They say that this research can happen. They say that it is safe and has been planned properly.</p>	
<p>Who is organising and funding the research?</p> <p>This research is funded by the UK Stroke Association. Development of the therapy app was funded by the UCL Therapeutic Acceleration Support scheme supported by funding from MRC Confidence in Concept 2020 UCL MC/PC/19054.</p>	
<p>Contact for further information</p> <p>If you need more information, please contact Fern Rodgers at f.rodgers@ucl.ac.uk Kerry Dathan at kerry.corley.16@ucl.ac.uk</p>	