Participant Information Sheet

Person with Aphasia

Title of the study:	**Measure for Dyadic Conversation in Aphasia (MDCA): Psychometric testing**
Principal Investigator:	Professor Katerina Hilari

Do you want to join a research study?

We are **inviting you** to take part in this research study. Before you decide, it is important you understand **why we are doing this research** and **what it involves.**

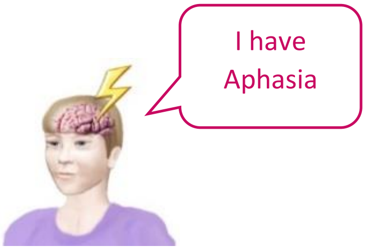
Please **read** this information carefully. You can also **talk about it** with your family and friends to help you decide. **Ask us** if there is anything that is not clear or if you need more information. We will give you a copy of this information sheet to keep.

- ## What is the purpose of the study?

Persons with aphasia have trouble communicating with other people. Even **conversations with close family and friends (partners) are affected**. Some aphasia therapy programmes help build the **skills of both the person with aphasia and their partner.** We need **assessments that capture** what people **do** and how they **feel** during **conversations with their partners**.

There is a NEW way to measure this: the **Measure for Dyadic Conversation in Aphasia (MDCA).** Both **persons with aphasia** and **their partners** complete the MDCA.

This project **will check** how well **MDCA works as a measure**. We will look at whether people can do it; what people think about it; what the scores tell us.



Why have I been invited?

You have been invited to take part because you:

- Are an **adult** with **aphasia** after a **stroke**

Do I have to take part?

No, it is **your choice**.

You can say 'yes' now, then **change your mind**. You don't have to say why. You can leave without any disadvantage to you. We will **still use** any **data** we got before you changed your mind.

This will **not** affect any other treatment or service you have.
If you **decide** to take part, you will be asked to sign a **consent form**.

What will happen if I take part?

You will meet researchers **2-3 times.** This can be **in person** or **online**, whatever you prefer.
In-person sessions will take place at your **home** and for online sessions you will log in from home. Unless you prefer **another setting.** In this case, we can book a room at the University, or a local community centre, or where an aphasia group meets.

1. **Visit 1: Screening and consent.** We expect this to take up to 1 hour
    - The researcher will ask you to complete a **short language assessment**.
    - They will check you **understand the study** and answer your questions.
    - They will ask you to **nominate a partner** (e.g., spouse, other relative, friend) to also take part.
    - They will ask you to **sign a consent form** if you want to take part.

2. **Visit 2:** This will be either **online or in person**. It will take about 1 hour
    - You will complete **4 (four) questionnaires/ measures**. The MDCA and other measures that ask about communication, mood, and quality of life
    - We will ask you about **your thoughts** about communication measures

3. **Visit 3:** This will be either **online or in person**. We expect this to take 20-30min.
    - You will complete the **MDCA** again. This tells us if MDCA gives the same result over time.
    - We will ask you about **your experience** with MDCA

If you choose to take part, you will be involved with the project for **2-3 weeks** and no more than a month.

We will only use **your name and contact details**, to get in touch with you **during your participation in the study**. We will then **destroy** it.

Your data will have a **code number** instead. This way your data that we keep will be **de-identified**.

• What do I have to do?

The questionnaires/ measures will involve:

- **Answering questions** about how you are **doing** and how you are **feeling**.
- They ask about **communication**, **feelings**, **relationships**, **mood** and **quality of life after stroke**.

UE6 DURING THE PAST WEEK

How much trouble did you have:

Opening a jar?

The questions about your **thoughts** about the communication measures will involve:

Checking how **easy** they were, how **relevant**, how well they captured your **conversations with your partner**.

• Can I choose how my information is used?

You can **stop being part of the study** at any time, without giving a reason, but we will **keep information** about you that we already have collected.

If you agree to take part in this study, you will **have the option** to share your **anonymised data** from this study **for future research**.

• Money

You will **not** be paid for taking part. We will cover **travel expenses**

• Are there any risks to taking part?

There are **no** medical **risks** or dangers. You will have to give up some of your **time**.

Some of the tasks may be **tiring**, or frustrating. If this happens, we can:

- have a **break**, or
- stop and carry on another time

You can leave the study at any time without having to continue later.

• Will the project help me?

We don’t know if the project will help you.

You will **learn** about your communication skills and **reflect** on your mood and quality of life. We have found that people are interested in understanding their condition better.

You will be **contributing** to tools that **improve clinical practice** and **create new knowledge** for the field of aphasia research.

Data privacy statement
City St George's, University of London is the sponsor and the data controller of this study based in the United Kingdom. This means that we are responsible for looking after your information and using it properly. The legal basis under which your data will be processed is City's public task.

Your rights to access, change or move your information are limited, as we need to manage your information in a specific way in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally identifiable information possible (for further information please see: https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/lawful-basis/a-guide-to-lawful-basis/public-task/).
City will use your name and contact details to contact you about the research study as necessary. The only people at City St George's who will have access to your identifiable information will be members of the research team, and, if appropriate, individuals with responsibility for monitoring and auditing at City St George's, including of research projects. There may be occasions when regulatory authorities may access research data in accordance with their statutory powers. City St George's will keep identifiable information about you from this study for 10 years after the study has finished.

You can find out more about how City handles personal data by visiting https://www.city.ac.uk/about/governance/policies/data-protection-policy. You can also read City's general privacy notice by visiting https://www.city.ac.uk/about/governance/policies/general-privacy-notice . If you are concerned about how we have processed your personal data, you can contact the Information Commissioner's Office (ICO) directly https://ico.org.uk/.

• What will happen to the results of the research?

We will **share** what we found out. We will

- write articles in scientific journals
- write articles in magazines for people who have had strokes
- share on social media
- talk about the research at conferences
- talk about the study at community groups

• Who has reviewed the study?

This study has been approved by City St George's, University of London (Clerkenwell and Moorgate Campuses) LCS Proportionate Review Committee of the School of Health and Medical Sciences Research Ethics Committee.

What if there is a problem?

If you have any **problems**, concerns, or **questions** about this study, you should ask to speak to a member of the research team.

If you remain unhappy and wish to **complain** formally, you can do this through City St George's complaints procedure. To complain about the study, you can contact the Research Governance, Ethics and Integrity Manager using the details below and inform them that the name of the project is **Measure for Dyadic Conversation in Aphasia (MDCA): Psychometric testing**

Research Governance, Ethics, and Integrity Manager
Research & Innovation Directorate
City St George's, University of London
Northampton Square
London, EC1V 0HB
Email: senaterec@city.ac.uk

Insurance

City St George's, University London holds insurance policies which apply to this study, subject to the terms and conditions of the policy. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action

Further information and contact details

Study Principal Investigator:

Katerina Hilari: ✉ k.hilari@citystgeorges.ac.uk ☎ 020 7040 4660

Thank you for taking the time to read this information sheet