

Participant Information Sheet Partner

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

Invitation to take part in a research study

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. You will be given a copy of this information sheet to keep.

What is the purpose of the study?

Those 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 the views of both the person with aphasia and their partner on how they feel and what they do during conversations.

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. We will look at whether people can do it; what people think about it; what the scores tell us. We will look at the MDCA's reliability and validity.

Why have I been invited to take part?

You have been invited to take part because a person with aphasia has nominated you as their communication partner. To take part in the study you need to be 18 years old or older and communicate with the person with aphasia at least 3 times a week.

Do I have to take part?

No, it is your choice. You can say 'yes' now if you wish and then change your mind. You don't have to say why. You can leave without any disadvantage to you or your partner with aphasia. We will keep any information about you that we have already.

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, on the phone, or online, whatever you prefer. In-person sessions will take place at your home and for online sessions you can 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.

1. **Visit 1: Screening and consent.** We expect this to take 20-30 min
 - The researcher will check you understand the study and answer your questions.
 - They will ask you to sign a consent form if you want to take part.

2. **Visit 2: Completing measures.** This will take about 30-40 min
 - You will complete three questionnaires/ measures. The MDCA and two other measures that ask about communication and mood.
 - We will ask you about your thoughts on the communication measures

3. **Visit 3:** This is **optional**. We expect this to take 20 min.
 - You will complete the MDCA again. This tells us if MDCA is a stable measure.
 - 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 your communication with your partner with aphasia, your relationship and your feelings. For the MDCA and the other communication measure we will also ask you how easy they were, how relevant, and 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.

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/>.

Compensation

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 get the chance to reflect on your communication with your partner with aphasia and your mood. We have found that people often find this interesting. You will be contributing to tools that improve clinical practice and create new knowledge for the field of aphasia research.

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:



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Thank you for taking the time to read this information sheet