

Ethics ETH2526-1074: Prof Katerina Hilari (Medium risk)

Date Created	20 Jan 2026
Date Submitted	06 Feb 2026
Academic Staff	Prof Katerina Hilari Prof Madeline Cruice Dr Sally McVicker Dr Abi Roper
Category	Academic Staff Academic Staff Academic Staff Academic Staff
Project	Measure for Dyadic Conversation in Aphasia (MDCA): Psychometric testing
School	School of Health & Medical Sciences
Department	Allied Health
Current status	Awaiting School of Health & Psychological Sciences Research Ethics Committee meeting

Ethics application

Risks

R1) Does the project have funding?

No

R2) Does the project involve human participants?

Yes

R3) Will the researcher be located outside of the UK during the conduct of the research?

No

R4) Will any part of the project be carried out under the auspices of an external organisation, involve collaboration between institutions, or involve data collection at an external organisation?

Yes

R5) Does your project involve access to, or use of, terrorist or extremist material that could be classified as security sensitive?

No

R6) Does the project involve the use of live animals?

No

R7) Does the project involve the use of animal tissue?

No

R8) Does the project involve accessing obscene materials?

No

R9) Does the project involve access to confidential business data (e.g. commercially sensitive data, trade secrets, minutes of internal meetings)?

No

R10) Does the project involve access to personal data (e.g. personnel or student records) not in the public domain?

Yes

R11) Does the project involve deviation from standard or routine clinical practice, outside of current guidelines?

No

R12) Will the project involve the potential for adverse impact on employment, social or financial standing?

No

R13) Will the project involve the potential for psychological distress, anxiety, humiliation or pain greater than that of normal life for the participant?

No

R14) Will the project be conducted or supported by any U.S. federal department or agency?

No

R15) Will the project involve research into illegal or criminal activity where there is a risk that the researcher will be placed in physical danger or in legal jeopardy?

No

R16) Will the project specifically recruit individuals who may be involved in illegal or criminal activity?

No

R17) Will the project involve engaging individuals who may be involved in terrorism, radicalisation, extremism or violent activity and other activity that falls within the Counter-Terrorism and Security Act (2015)?

No

Applicant & research team

T1) Principal Applicant

Name

[Prof Katerina Hilari](#)

Provide a summary of the researcher's training and experience that is relevant to this research project.

Professor Hilari is an aphasia expert SLT researcher. She is an expert on outcome measurement for people with aphasia. She has led multiple aphasia projects, including psychometric studies, and has supervised multiple students in their research.

T2) Co-Applicant(s) at City

Name

[Prof Madeline Cruice](#)

Provide a summary of the researcher's training and experience that is relevant to this research project.

Professor Cruice is an aphasia expert SLT researcher. She co-leads the APT research project (see below) that this project is contributing to. She has led multiple aphasia projects and has supervised multiple students in their research.

Name

[Dr Sally McVicker](#)

Provide a summary of the researcher's training and experience that is relevant to this research project.

Dr McVicker is an aphasia expert SLT clinician, and experienced practice educator and aphasia researcher. She leads Aphasia ReConnect a charity for people with aphasia that will assist with recruitment and data collection.

Name

[Dr Abi Roper](#)

Provide a summary of the researcher's training and experience that is relevant to this research project.

Dr Abi Roper is an aphasia expert SLT clinician, and computer scientist. She has led many aphasia projects with tech applications. She will assist with tech aspects of the project and online data forms for data collection.

T3) External Co-Applicant(s)

T5) Do any of the investigators have direct personal involvement in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

No

T6) Will any of the investigators receive any personal benefits or incentives, including payment above normal salary, from undertaking the research or from the results of the research above those normally associated with scholarly activity?

No

T7) List anyone else involved in the project.

This project is an add-on project to an NIHR PGfAR funded project: the Aphasia Partnership Training (APT) project. APT is co-led by Professor Madeline Cruice at City and Professor Rebecca Palmer at the University of Sheffield.

Dr Sharon Adjei-Nicol and Natascha Ullrich are experienced SLTs, members of the APT team and will assist with data collection.

Dr Annette Rotherham is the developer of the MDCA. She will assist with the interpretation of the data.

Dr Silia Vitoratou, from Kings College London is a Psychometric statistician and will oversee the data analysis of this project.

Dr Sally McVicker, as well as a staff member at City St George's, leads Aphasia ReConnect, a charity for people with aphasia. Aphasia ReConnect has agreed to support this project with recruitment and data collection (City SLT students in placement) as the MDCA is an interesting outcome for their services.

We also plan to supervise student projects within this study. We will also invite student volunteers who wish to increase their experience with people with aphasia to collect data for this project. These student names will be added on to the application through amendments once confirmed.

Project details

P1) Project title

Measure for Dyadic Conversation in Aphasia (MDCA): Psychometric testing

P1.1) Short project title

MDCA - Psychometrics

P2) Provide a lay summary of the background and aims of the research, including the research questions (max 400 words).

BACKGROUND:

Communication partner training (CPT) is an intervention for people with aphasia and their partners that aims to improve the communication skills of both partners, in order to improve their conversations. One CPT programme developed by our team (led by Professor Madeline Cruice from City St George's and Professor Rebecca Palmer from University of Sheffield) is Aphasia Partnership Training (APT). We have previous and continuous work with APT and we need appropriate outcome measures to measure the intended outcomes of APT.

NEED FOR THE STUDY:

Available outcome measures for communication typically look at the skills of just the person with aphasia. Very few measures exist that capture the communication skills of both partners (dyadic communication), which is the key intended outcome of CPT and APT. In our previous work, we have

evaluated the psychometric properties of existing measures and they are limited (publication pending).

THE CURRENT STUDY'S AIM:

A new measure has been recently developed called Measure of Dyadic Conversation in Aphasia (MDCA). MDCA has been developed following COSMIN guidelines for patient reported outcome measures and has very good content validity (Rotherham, 2025 PhD thesis available <https://espace.library.uq.edu.au/view/UQ:a647829>). This project aims to begin the process of testing the psychometric properties of MDCA.

RESEARCH QUESTIONS:

Specifically the following research questions will be addressed;

- 1) What is the reliability (internal consistency; stability) of MDCA with community dwelling people with stroke and aphasia and their primary communication partners.
- 2) What is the construct validity of MDCA with community dwelling people with stroke and aphasia and their primary communication partners.
- 3) What is the relationship (correlation) of the PWA (MDCA-A) and communication partner (MDCA-P) versions of MDCA

P4) Provide a summary and brief explanation of the research design, method, and data analysis.

DESIGN:

The study will be an interview-based, cross-sectional, psychometric study.

PROCEDURE AND METHOD:

Potential participants will have initial information about the project through an ad or information from their referring group facilitator or clinician. Those expressing an interest to take part will be given the participant information sheet and will be seen by a project researcher. They will be seen at a location of their choice (e.g., online or at home or a community setting) and the researcher will give them full information about the project and check their eligibility to take part. Those with aphasia will also complete a screening test (Frenchay Aphasia Screening Test, FAST short version) to ensure they have adequate comprehension to understand what the study entails. Verbal and/or written consent will be obtained. This first visit will take about 45min and no more than 1 hour.

Those expressing an interest to take part will be visited a second time. Consent will be confirmed at this visit. Participants will then complete the MDCA and a selection of other outcome measures to capture the intended outcomes of APT (Palmer et al., 2025). These will comprise communication (the Communicative Participation Item Bank, CPIB for PWA; the Communicative Effectiveness Index, CETI, for Partners), thoughts and feelings (the General Health Questionnaire, GHQ-12; Stroke and Aphasia Quality of Life scale, SAQOL-39g PWA). The researcher will also complete the Therapy Outcome Measures for Aphasia (TOMs). Participants will also be briefly asked about what they thought of the MDCA and how well communication measures used captured their communication with their partner. Testing with participants with aphasia is anticipated to take about 1 hour, 1hr 15min (short case history form, FAST, MDCA-A, CPIB, GHQ-12, SAQOL-39g); and less than 1 hour (30-40min) with communication partners (short case history form, MDCA-P, GHQ-12, CETI).

Participants will then be seen one more time to complete the MDCA again for test-retest reliability purposes (~20min).

DATA ANALYSIS:

Descriptive statistics will be used to describe participant characteristics and their performance/scores on the measures used. Missing data (%) will inform acceptability. Internal consistency indices will comprise Cronbach's alpha, alpha if item deleted, item-total and inter-item correlations. Correlation statistics will be used for construct validity, and relationship between MDCA-A and MDCA-P testing. We anticipate moderate to high correlations between MDCA communication items and CPIB, CETI, TOMs activity and participation, SAQOL-39g, and GHQ-12. Moderate correlations are anticipated between MDCA relationship items and GHQ-12 and SAQOL39 psychosocial domain. Lower correlations are expected between MDCA and FAST, SAQOL-39 physical, and TOMs impairment. For test re-test reliability, suitable measures of agreement will be used on item and total score level based on the distribution properties of the variables involved (Psi coefficient for ordinal and skewed data, and Intraclass Correlation Coefficient for symmetrical data, for instance). Established guidelines will be followed for interpretation.

P4.1) If relevant, please upload your research protocol.

P5) What do you consider are the ethical issues associated with conducting this research and how do you propose to address them?

The project is low risk as it involves assessing people with aphasia and their communication partners on established measures of language, communication, and feelings, and a new measure developed through co-design with them. There still remain ethical considerations.

INFORMED CONSENT. For all participants clear information will be provided to ensure they understand what the project entails. Information will highlight that participation is entirely voluntary. In addition for those with aphasia, an experienced speech and language therapist researcher (SLT) or SLT student trained in communicating with people with aphasia will provide information on the project and check participant's understanding of information provided and willingness to take part. To support informed consent for those with aphasia:

- o Participant Information (PIS) will be provided in an aphasia accessible format
- o A minimum comprehension criterion on the FAST at screening will be used (≥ 7 on receptive domains).

CONFIDENTIALITY. Data must be kept confidential and stored securely. To this end:

- o Data about participants will be stored securely on the encrypted, password protected City St George's University of London OneDrive.
- o Participants consent to any data collection
- o Identifying information (consent forms) kept separately to study data.

DISTRESS AND BURDEN. Participants must not be over burdened.

- o The participants with aphasia' diagnoses and symptoms may already be stressful and emotional. It will be clear that study participation is voluntary, and participants can withdraw at any time without giving a reason. This will be explained to them.

- o Sometimes completing assessments (language, feelings, relationships) can be upsetting for people with aphasia as it highlights their disability. Researchers will offer breaks, time to talk, and can reschedule. Researchers will be trained to share information for further services when these are indicated e.g., local support groups, a GP referral for psychological support
- o Testing sessions will be time limited. Participants will be offered regular breaks and refreshments as needed. If a participant appears tired they will be given the option of an alternative/additional session.

P6) Project start date

The start date will be the date of approval.

P7) Anticipated project end date

30 Jun 2027

P8) Where will the research take place?

Sessions will take place either online or at a location of participants's choice, e.g. their home, a stroke and aphasia community group meeting place, a quiet place in their locality.

P10) Is this application or any part of this research project being submitted to another ethics committee, or has it previously been submitted to an ethics committee?

No

External organisations

E1) Provide details of the external organisation/institution involved with this project.

Aphasia ReConnect, a charity for people with aphasia, is a partner in this project. They are interested in the MDCA as an outcome measure for their services and are keen to collaborate in the testing of the measure. They will support the project through referring participants and collecting data. The collaborating clinician at Aphasia ReConnect is a City St George's staff member and has City SLT students on placement. These students get experience with measuring outcomes with people with aphasia as part of their placement and can collect data with the proposed measures for this study.

The University of Sheffield. Data will also be collected in and around Sheffield through members of the APT research team at that location (listed in this application (Natascha Ullrich)). Sheffield Aphasia Centre takes Sheffield SLT students on placement and they are happy to collect data for the project. Following City St George's ethics review, additional approval will be sought from University of Sheffield.

E2) If applicable, has permission to conduct research in, at or through another institution or organisation been obtained?

Yes

E2.1) Provide details and attach the correspondence.

Following City St George's ethics review, the University of Sheffield will follow their process for permission for data collection at that site.

Human participants: information and participation

The options for the following question are one or more of:

'Under 18'; 'Adults at risk'; 'Individuals aged 16 and over potentially without the capacity to consent'; 'None of the above'.

H1) Will persons from any of the following groups be participating in the project?

Adults at risk

H2) How many participants will be recruited?

200

H3) Explain how the sample size has been determined.

Our expert psychometrics statistician Dr Silia Vitoratou Psychometrics and Measurement Lab, Biostatistics and Health informatics, IoPPN, King's College London, who is a collaborator on the project, has calculated power, and advised on data analysis.

Psychometric studies require large samples. We will aim for 100 PWA and as many partners as we can recruit and no more than 100. For each of the subgroups, with 100 individuals, 80% power is achieved in detecting modest agreement according to ICC=0.8 (power calculated at alpha=0.05 using the ICC package in R).(1) This sample results to power >0.80 for internal consistency analysis with alpha levels close to 0.80.(2)

References:

1. Zou GY. Sample size formulas for estimating ICC with precision and assurance. Stat Med. 2012;31:3972-3981.
2. Heo M, et al. Statistical power as a function of Cronbach alpha of instrument questionnaire items. BMC Medical Research Methodology. 2015:86.

H4) What is the age group of the participants?

Lower Upper

18

H5) Please specify inclusion and exclusion criteria.

Information on criteria below will be collected from participants through a case history form and also, for those referred to the study, from the referring source (e.g., SLT, group co-ordinator).

PARTICIPANTS WITH APHASIA:

Inclusion criteria: aged 18+ years; aphasia subsequent to stroke(s) at least 3 month prior to consent; score ≥ 7 on receptive domains of FAST to ensure capacity to consent. Optional: able to identify a regular communication partner who is willing to take part in the study too.

Exclusion criteria: have another speech and language disorder caused by a neurological deficit other than stroke; still in an acute hospital; have uncorrected visual or hearing problems; have a cognitive difficulty that is considered to limit their ability to respond reliably to questionnaires; have other severe or potentially terminal comorbidity on grounds of frailty.

COMMUNICATION PARTNERS

Inclusion criteria: aged 18+ years; communication partner for the consenting PWA; communicate with the PWA at least 3 times a week.

Exclusion criteria: have uncorrected visual or hearing problems; have a cognitive difficulty that is considered to limit their ability to respond reliably to questionnaires; have severe or potentially terminal comorbidity on grounds of frailty.

H6) What are the potential risks and burdens for research participants and how will you minimise them?

The project is very low risk as it involves assessing people with aphasia on established measures of communication, wellbeing/mood and quality of life. It is possible that some questions in these assessments may upset a participant. The researchers will be aphasia-expert SLTs, or SLT students supervised by aphasia expert SLTs, with skills to support participants. The assessment will be paused or stopped and resumed at another time and the issue discussed.

It is also possible that the wellbeing measure may identify that participants suffer from high emotional distress/depression. On such occasions this finding will be discussed with the participant and a course of action will be agreed. Support will be provided to implement this plan. This may involve raising this finding (with their consent) or encouraging them to raise this with their referring clinician (if applicable) and/or seek support with GP. It may involve supporting them to make contact and complete e-health consultation requests. Where appropriate, we may recommend and help participants to contact support organisations such as the Stroke Association, Aphasia Re-Connect or other local groups.

H7) Will you specifically recruit pregnant women, women in labour, or women who have had a recent stillbirth or miscarriage (within the last 12 months)?

No

H8) Will you directly recruit any staff and/or students at City?

None of the above

H8.1) If you intend to contact staff/students directly for recruitment purpose, please upload a letter of approval from the respective School(s)/Department(s).

H9) How are participants to be identified, approached and recruited, and by whom?

We will advertise the project on social media, to third-sector organisations and people known to the broader APT project and the University who have given permission to be contacted for research. We will share information with local aphasia support groups, provide project information and answer any questions. Initial eligibility (adult, aphasia due to stroke, >3m post onset) will be checked by group facilitators or project researchers.

If someone is interested in taking part, they will receive the participant information sheet. They will then have a session with a project researcher (SLT or SLT student). They will be given full information on the project and answer questions. Researchers will check criteria based on participant self-report and information from carers/partners, and those with aphasia will be screened with the FAST. Consent will be obtained (verbal and/ or written). Consent will be confirmed in the first data collection visit approximately 1 week later (at least 3 days later).

H10) Please upload your participant information sheets and consent form, or if they are online (e.g. on Qualtrics) paste the link below.

H11) If appropriate, please upload a copy of the advertisement, including recruitment emails, flyers or letter.

H12) Describe the procedure that will be used when seeking and obtaining consent, including when consent will be obtained.

a) A member of the research team (including student SLTs trained in communication with people with aphasia and consent processes) will complete the screening assessment (The Frenchay Aphasia Screening Test, 10mins) and check inclusion criteria. If they meet criteria the researcher will go through the PIS and answer any questions they have about the project. Then they will be asked if they would like to take part. If they would, they will be invited to complete the consent form.

b) A copy will be kept for researchers file and a copy will be left with the participant (emailed if consent completed online).

c) The PIS was given when interest was first expressed (see H9)

d) At least 3 days

H13) Are there any pressures that may make it difficult for participants to refuse to take part in the project?

No

H14) Is any part of the research being conducted with participants outside the UK?

No

Human participants: method

The options for the following question are one or more of:

'Invasive procedures (for example medical or surgical)'; 'Intrusive procedures (for example psychological or social)'; 'Potentially harmful procedures of any kind'; 'Drugs, placebos, or other substances administered to participants'; 'None of the above'.

M1) Will any of the following methods be involved in the project:

None of the above

M2) Does the project involve any deceptive research practices?

No

M3) Is there a possibility for over-research of participants?

Yes

M3.1) What steps will be taken to safeguard the participants from over-research?

We will ask potential participants if they are involved in any other research projects and if they are feeling overburdened. People approached are under no obligation to take part in the research and this will be made clear. People with aphasia report feelings of isolation following the stroke and value the opportunity for both altruism and/or social contact that comes with being involved in research.

M4) Please upload copies of any questionnaires, topic guides for interviews or focus groups, or equivalent research materials.

M5) Will participants be provided with the findings or outcomes of the project?

Yes

M5.1) Explain how this information will be provided.

Participants can request that their assessment scores are shared with them. We will not share results directly with participants as we will not keep their contact details.

At the end of the project, we will share results about the study on our City Access Resources for Aphasia website, through publications read by users (e.g. Aphasia ReConnect newsletter, Stroke Association newsletters) and social media.

M6) If the research is intended to benefit the participants, third parties or the local community, please give details.

The research will not benefit the participants directly. However, it will generate evidence on outcome measures (MDCA-A and MDCA-P) that are needed in clinical practice and research with people with aphasia.

M7) Are you offering any incentives for participating?

No

M8) Does the research involve clinical trial or clinical intervention testing that does not require Health Research Authority or MHRA approval?

No

M9) Will the project involve the collection of human tissue or other biological samples that does not fall under the Human Tissue Act (2004) that does not require Health Research Authority Research Ethics Service approval?

No

M10) Will the project involve potentially sensitive topics, such as participants' sexual behaviour, their legal or political behaviour, their experience of violence?

No

M11) Will the project involve activities that may lead to 'labelling' either by the researcher (e.g. categorisation) or by the participant (e.g. 'I'm stupid', 'I'm not normal')?

No

Human participants: vulnerable

V1) Please provide details of enhanced ethical procedures to safeguard these participants.

Aphasia is a language impairment. Participants with aphasia are at risk of not being informed fully if information and consent materials are not adjusted. Aphasia is not a cognitive impairment. People with aphasia therefore have the capacity to give informed consent, providing there are no comorbidities that affect cognition and providing that information is presented in an accessible

manner. If there are doubts about capacity, an individual will not be consented into the trial. Consent and information materials have been designed to be accessible to people with aphasia. We also screen participants' aphasia (FAST) to ensure they have adequate understanding. The researchers are speech and language therapists who are experienced in working with people who have aphasia and in recruiting research participants from this population or SLT students who will be trained in these processes.

V2) Please give details of the vulnerable participant protection procedures you propose to adopt should there be any evidence or suspicion of harm (physical, emotional or sexual) to a vulnerable person. Include a referral protocol identifying what to do and who should be contacted.

All research will be undertaken either by, or under the supervision of a qualified Speech and Language Therapist, able to discuss relevant issues in an accessible manner. Evidence &/or suspicion of harm will be raised immediately with the project PI (Katerina Hilari). Steps taken will meet the responsibilities of The Care Act 2014. For example, the researcher will: Assess the situation; Ensure the safety and wellbeing of the participant; Establish the participant's views and wishes about the safeguarding issue; Ensure that any evidence is maintained; Make appropriate reports and referrals, e.g., to the Participant's G.P. or relevant Social Services or Health Trust Officer; Inform the participant about what information is being shared and why; Document the episode using the participant's own words, and Record what has been seen and any actions taken. If there are concerns about the participant's immediate safety the researcher will ensure that protection (e.g., from the police) or medical assistance has been sought. Any referrals may be made initially by phone (to ensure speed) but will be confirmed in writing within 2 working days. We will follow the guidance laid out in 'Safeguarding Adults' (NHS England):

<https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2016/04/1085-nhs-leaflet-accessible-copy.pdf>. If unmet health needs are disclosed, we will ask consent of the participant to write to their GP informing them of the unmet need. If unmet care needs are disclosed, we will seek consent to discuss these with relevant family members &/or Social Services.

V3) Please give details of how you propose to ensure the well-being of the vulnerable participant, particularly with respect to ensuring that they do not feel pressured to take part in the research and that they are free to withdraw from the research without any prejudice to themselves at any time.

Participants will be informed that they are free to withdraw at any time without giving any reason, and that this will not affect them in any way and where applicable it will not affect any other care that they might be receiving. Participants are not in a dependent relationship with the researchers. Participants recruited through communication or stroke support

groups are typically discharged from Speech and Language Therapy services. Participation will not, therefore, impact upon other forms of rehabilitation. However, participants will be reassured that not participating will not affect their support or attendance at the support groups.

V4) Will carers, parents, teachers or other parties be present during the research?

No

V5) Are participants able to give informed consent?

Yes

V6) Please give details of any City staff or students who will have contact with adults at risk and/or will have contact with young people (under the age of 18) and the details of current (within the last 3 years) Disclosure and Barring check.

Name

[Dr Sally McVicker](#)

DBS reference number

001635043048

Date of DBS

24 Oct 2025

Type of Disclosure

Enhanced.

V7) Please give details of any non-City staff or students who will have contact with adults at risk and/or will have contact with young people (under the age of 18) and the details of current (within the last 3 years) Disclosure and Barring check.

Name

Sharon Adjei-Nicol

Institution

SLT in private practice

Address of organisation that requested disclosure

The Marillac Neurological Care Centre

Eagle Way

Brentwood

Essex

CM13 3BL

DBS reference number

001869471860

Date of DBS

29 Feb 2024

Type of disclosure

Enhanced

Name

Natascha Ullrich

Institution

Sheffield Teaching Hospitals NHS Foundation Trust

Address of organisation that requested disclosure

Sheffield Teaching Hospitals NHS Foundation Trust

Royal Hallamshire Hospital,

Glossop Road

Sheffield S10 2JF

DBS reference number

001938850377

Date of DBS

05 Sept 2025

Type of disclosure

Enhanced

I will not be recruiting any participants who fall under the Mental Capacity Act 2005.

Data

D1) Indicate which of the following you will be using to collect your data.

Questionnaire

Computer-based tasks, screen recording or software instrumentation

D2) How will the the privacy of the participants be protected?

Anonymised sample or data

D3) Will the research involve use of direct quotes?

No

D5) Where/how do you intend to store your data?

Data to be kept in a locked filing cabinet

Password protected computer files

Storage at City

Storage at other site

D5.1) If stored at another site, please provide details.

Some data will not be collected by City researchers. We have minimised the need to store data at another site in the following ways. We have Qualtrics forms to support data collection in this project

for consent forms, case history information, CPIB, GHQ-12, SAQOL-39. Researchers can enter data directly to City Qualtrics forms during data collection for these measures.

We plan to create similar Qualtrics forms for the remaining measures (MDCA-A, MDCA-P, CETI, experience questions). In the meantime and also as back up when devices may not be available, hard copy data may also be collected. These will be stored in locked filing cabinets. Researchers collecting data will be given access to a City One Drive folder to upload scanned forms, as soon as possible after data collection. Once forms are uploaded, hard copies and scans will be destroyed.

Each person or group of persons from one setting (e.g., Sheffield, Aphasia ReConnect) will have access to their unique folder so that they cannot access other participants data. This folder will regularly be emptied with data transferred to the City research team's OneDrive folder for storage and analysis.

D6) Will personal data collected be shared with other organisations?

Yes

D6.1) Will the other organisation be a joint data controller with City or a data processor on behalf of City?

Data processor

D6.2) Detail the scope of any data sharing requirements (joint data controller) or data processing contract (data processor on behalf of City) with the other organisation.

Anonymised dataset from the project will be shared with the project statistician who is based at Kings College London. This will be outlined in a data processing agreement.

D7) Will the data be accessed by people other than the named researcher, supervisors or examiners?

Yes

D7.1) Explain by whom and for what purposes.

We aim to offer this project as a student project to SLT students in pre-reg and post-reg programmes. These students working under our supervision will be named /added to the application when known and they will be DBS checked speech and language therapy students.

D8) Is the data intended or required (e.g. by funding body) to be published for reuse or to be shared as part of longitudinal research or a different/wider research project now or in the future?

Yes

D9) Does the funding body or your professional organisation/affiliation place obligations or recommendations on the retention and destruction of research data?

Yes

D9.1) What are your affiliations/funding and what are the requirements?

City St George's is the affiliation. Psychometric studies require large data sets for further analyses (e.g. ~300 for factor analysis). We may be involved in further projects testing the psychometrics of

MDCA. It will be specified in the PIS and CF that anonymised data may be shared with other researchers for future research and explicit consent will be sought.

D10) How long are you intending to keep the research data generated by the study?

As per University guidelines 10 years.

D11) How long will personal data be stored or accessed after the study has ended?

10 years

D12) How are you intending to destroy the personal data after this period?

All stored data will be digital data that will be deleted from the City University OneDrive and computer bin will be emptied.

Health & safety

HS1) Are there any health and safety risks to the researchers over and above that of their normal working life?

Yes

HS2) How have you addressed the health and safety concerns of the researchers and any other people impacted by this project?

It is anticipated that most visits will be online or public space, e.g. University clinic, a community group setting. Researchers will also go on home visits. Home visits are part of a researcher's and a clinician's normal working life. Researchers will follow City St George's University of London's lone worker policy to mitigate any potential risks e.g., calendars are shared so team members know where they are, they will text a colleague on arrival and when leaving. The researchers on the team are experienced clinicians or SLT students under their supervision and therefore have the experience to assess possible risk and take appropriate action.

HS3) Are there hazards associated with undertaking this project where a formal risk assessment would be required?

No

Attached files

Sheffield letter.pdf

MDCA Psychometrics PIS Partner V1.docx

MDCA Psychometrics PIS PWA V1.docx

MDCA Psychometrics CF Partner V1.docx

MDCA Psychometrics CF PWA V1.docx

MDCA recruitment flyer.docx

CETI.pdf

MDCA Test Version (1).pdf

SAQOL-39g scoring sheet.pdf

GHQ12 updated Sept 2015.pdf

FAST.RecordForm.pdf

CPIB.pdf

MDCA Psychometrics CaseHistory PWA.docx

MDCA Psychometrics CaseHistory Partner.docx

MDCA Psychometrics Review Qs.docx

Measure for Dyadic Conversation in Aphasia (MDCA) testing

From Rebecca Palmer <r.l.palmer@sheffield.ac.uk>

Date Wed 2026-02-04 16:18

To Hilari, Katerina <K.Hilari@citystgeorges.ac.uk>

CAUTION: This email originated from outside of the organisation. Do not click links or open attachments unless you recognise the sender and believe the content to be safe.

Dear Katerina,

Re Measure for Dyadic Conversation in Aphasia (MDCA) testing : Psychometric testing

Thank you for leading on the psychometric testing of the MDCA.

As collaborators on this at the University of Sheffield we are happy with City leading on the ethics application (ethics ref ETH2526-1074).

We will seek additional approvals/permissions required by The University of Sheffield.

Best wishes,
Rebecca

--

Rebecca Palmer
Professor of Communication and Stroke Rehabilitation
MSc Clinical Research programme director

Sheffield Centre for Health and Related Research (SCHARR)
Division of Population Health
School of Medicine and Population Health
University of Sheffield
1024 Regent Court
Regent Street
S1 4DA

Participant Information Sheet Partner

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?

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 measures that capture the views of both people with aphasia and their partners on how they feel and what they do during conversations.

There is a NEW measure for 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. 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, and neither you nor your partner with aphasia will be penalised in any way. We will use any data we have collected before you leave the study.

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, what 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 anonymised.

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 the internet; 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

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 **measures that capture** what people **do** and how they **feel** during **conversations with their partners**.

There is a NEW measure for 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, and you will not be penalised in any way. We will **use data** we have got before you change 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**, what 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 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 **anonymous**.



- **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**.

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/>).

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- **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 the internet
- 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



Participant Consent Form - Partner

Title of the study: Measure for Dyadic Conversation in Aphasia (MDCA): Psychometric testing

Principal Investigator: Professor Katerina Hilari

I **confirm** that I have read the Participant Information Sheet V1, dated 04.02.2026 for the above study. I have had the opportunity to consider the information and ask questions which have been answered satisfactorily.

I **understand** the project will involve:

please initial
the box

- a. completing the MDCA and two other measures about communication and mood
- b. these will be online, on the phone and/or in-person
- c. a researcher asking me about my views on the communication measures

☐

I understand that my participation is **voluntary** and that I am **free to withdraw** without giving a reason and without being penalised or disadvantaged.

☐

I agree to City St George's recording and processing this information about me. I understand that this information will be used **only for the purpose(s) explained** in the participant information and my consent is conditional on City complying with its duties and obligations under the General Data Protection Regulation (GDPR).

☐

I understand that the information collected about me will be used to support other research in the future and may be **shared anonymously** with other researchers.

☐

I agree to take part in the above study

☐

Name of Participant Signature Date

Name of Researcher Signature Date

MDCA Psychometrics Study Participant Consent form (ETH2526-1074) V1 | 04/02/2026

Commented [KH1]: This is for back up hard copy form.

The consent form is intended to be on Qualtrics. On the digital form participants will have to click statements above, last statement will be removed and they will have to click 'I consent' (vs 'I do not consent') to take part in the study.

Participant Consent Form

Title of the study: Measure for Dyadic Conversation in Aphasia (MDCA): Psychometric testing

Principal Investigator: Professor Katerina Hilari

1. I **confirm** that I have read the Participant Information Sheet V1, dated 04.02.2026 for the above study. I have had the opportunity to consider the information and ask questions which have been answered satisfactorily.

I **understand** the project will involve:

please initial or
mark the box

- completing **questionnaires / measures** about my communication, mood and quality of life



- these will be **online** and/or **in-person**



- a researcher asking me about my **experience of measures**



2. I understand that my participation is **voluntary** and that I am **free to withdraw** without giving a reason and without being penalised or disadvantaged.

3. I agree to City St George's recording and processing this information about me. I understand that this information will be used **only for the purpose(s) explained** in the participant information and my consent is conditional on City complying with its duties and obligations under the General Data Protection Regulation (GDPR).

4. I understand that the information collected about me will be used to **support other research** in the future and may be **shared anonymously** with other researchers.

☐

5. **I agree** to take part in the above study

☐

Your name

Date

Signature

Name of researcher

Date

Signature

1 copy for participant and 1 copy for researcher file

Commented [KH1]: This is for back up hard copy form.

The consent form is intended to be on Qualtrics. On the digital form participants will have to click on the statements above, statement 5 will be removed and they will have to click 'I consent' (vs 'I do not consent') to take part in the study.

PARTICIPANTS NEEDED FOR RESEARCH IN APHASIA

Conversations are hard when you have aphasia! We need better tools to capture problems in conversations to see what we can do about them.



We are looking for volunteers to take part in a study to test **a new measure on conversations for people with aphasia and their partners.**

As a participant in this study, we would ask you to:

- Complete **3-4 measures on conversations with your partner, communication, feelings and quality of life**
- Your participation would involve **three sessions**, each of which is approximately 30 – 60 minutes.
- We can see you **on-line or in-person**, whatever suits you best

For more information about this study, or to volunteer for this study,
please contact:

(insert name of contact person, including supervisor if it's a student project)

(insert QR code)

at

Email: *(add email address, valid City St George's or partner email address)*

This study has been reviewed by and received ethics clearance through the LCS Proportionate Review Committee, City St George's, University of London.

16 Items of the Communicative Effectiveness Index (CETI)

from Lomas, J., Pickard, L., Bester, S., Elbard, H., Finlayson, A., & Zoghaib, C. (1989). The Communicative Effectiveness Index: Development and psychometric evaluation of a functional communication measure for adult aphasia. *Journal of Speech and Hearing Disorders*, 54, 113-124. As cited in Chapey, R. (Ed.). (2008). *Language intervention strategies in aphasia and related neurogenic communication disorders* (5th ed.). Philadelphia, PA: Lippincott Williams & Williams.

Please rate _____'s performance for each particular communication situation.

Getting somebody's attention.	Not at all able -----as able as before
Getting involved in group conversations that are about him or her.	Not at all able -----as able as before
Giving yes and no answers appropriately.	Not at all able -----as able as before
Communicating his or her emotions.	Not at all able -----as able as before
Indicating that he or she understands what is being said to him or her.	Not at all able -----as able as before
Having coffee-time visits and conversations with friends and neighbors (around the bedside or at home).	Not at all able -----as able as before
Having a one-to-one conversation with you.	Not at all able -----as able as before
Saying the name of someone whose face is in front of him or her.	Not at all able -----as able as before
Communicating physical problems such as aches and pains.	Not at all able -----as able as before
Having a spontaneous conversation (e.g., starting the conversation and/or changing the subject).	Not at all able -----as able as before
Responding to or communicating anything (including yes and no) without words.	Not at all able -----as able as before
Starting a conversation with people who are not close family.	Not at all able -----as able as before
Understanding writing.	Not at all able -----as able as before
Being part of a conversation when it is fast and a number of people are involved.	Not at all able -----as able as before
Participating in a conversation with strangers.	Not at all able -----as able as before
Describing or discussing something in-depth.	Not at all able -----as able as before

MDCA Test Version

The Measure of Dyadic Conversation in Aphasia

MDCA- Test Version

MDCA- Aphasia

The MDCA aims to measure successful conversations in couples where one person has aphasia. The MDCA measures the success of communication and coping strategies, as well as the mindset and attitudes of the couple or dyad. The MDCA aims to help clinicians identify strengths and areas that could be enhanced in conversations with both conversation partners. This will support goal-setting and couple conversation therapy planning in aphasia rehabilitation.

The items in the MDCA have been developed by examining existing measures of conversation and in partnership with people living with aphasia. This has included asking people with aphasia and their communication partners, "What makes their conversations successful?"

The MDCA has had face and content validation but requires further psychometric testing before the scores can be used meaningfully.

Administration:

There are two versions of the MDCA, one for the person with aphasia and one for their primary conversation partner. This is the version for the *person with aphasia*.

The administering clinician should describe the scale and ask the person with aphasia to consider conversations with their primary conversation partner in the last month and what has made conversations successful. Try to treat the items as an interview and note any other points made.

Frequency Scale: The following rating scale is used throughout.

How often have the following strategies helped to facilitate successful conversations with your conversation partner?

In the last month...

1	2	3	4	5
never	rarely	sometimes	often	always

Domain 1- Working together- Interaction (Person with Aphasia)

How often have the following strategies helped to facilitate successful conversations with your conversation partner?

In the last month...

1	2	3	4	5
never	rarely	sometimes	often	always

Domain 1- Working together- Interaction

**Frequency
Rating**

- | | |
|--|-----------|
| 1. I repeated if _____(name) didn't understand. | 1 2 3 4 5 |
| 2. _____(name) repeated what they said to help me understand. | 1 2 3 4 5 |
| 3. _____(name) asked questions to clarify what I meant. | 1 2 3 4 5 |
| 4. _____(name) allowed time for me to speak. | 1 2 3 4 5 |
| 5. I was able to express my ideas and opinions . | 1 2 3 4 5 |
| 6. We both initiated conversations with each other. | 1 2 3 4 5 |
| 7. I could tell _____(name) what was important to me. | 1 2 3 4 5 |
| 8. _____(name) listened carefully to me. | 1 2 3 4 5 |

Note any further thoughts and ideas expressed by the person with aphasia:

Domain 2: Other ways of communicating- Multimodal communication (Person with Aphasia)

How often have the following strategies helped to facilitate successful conversations with your conversation partner?

In the last month...

1 _____ 2 _____ 3 _____ 4 _____ 5
never rarely sometimes often always

Domain 2: Other ways of communicating- Multimodal communication

**Agreement
Rating**

- | | |
|--|-----------|
| 1. _____(name) wrote keywords down. | 1 2 3 4 5 |
| 2. We used gestures, body language and facial expressions to communicate. | 1 2 3 4 5 |
| 3. We used technology to support our conversations
e.g. phone, tablet, maps, photos. | 1 2 3 4 5 |
| 4. We made sure we looked at each other when talking. | 1 2 3 4 5 |

Note any further thoughts and ideas expressed by the person with aphasia:

Domain 3: Familiarity and the Communication Environment – Context/Common Ground (Person with Aphasia)

How often have the following strategies helped to facilitate successful conversations with your conversation partner?

In the last month...

1 _____ 2 _____ 3 _____ 4 _____ 5 _____
never rarely sometimes often always

Domain 3A: Familiarity - Common Ground

**Frequency
Rating**

- | | |
|---|-----------|
| 1. We talked about topics we were both interested in. | 1 2 3 4 5 |
| 2. _____(name) understands my aphasia | 1 2 3 4 5 |
| 3. Our shared routines, memories and background- helped our conversations. | 1 2 3 4 5 |

Domain 3B: Considering the Environment- Context and Common Ground

**Frequency
Rating**

- | | |
|---|-----------|
| 4. We reduced noise and distractions. | 1 2 3 4 5 |
| 5. We communicated one-on-one | 1 2 3 4 5 |
| 6. We came back to it later if _____(name) couldn't work it out. | 1 2 3 4 5 |
| 7. We kept conversations shorter if I was tired. | 1 2 3 4 5 |

Note any further thoughts and ideas expressed by the person with aphasia:

Domain 4: Managing the impact of aphasia - Mindset and Attitude (Person with Aphasia)

How often have the following strategies helped to facilitate successful conversations with your conversation partner?

In the last month...

1 _____ 2 _____ 3 _____ 4 _____ 5
never rarely sometimes often always

Domain 4: Managing the impact of aphasia - Mindset and Attitude

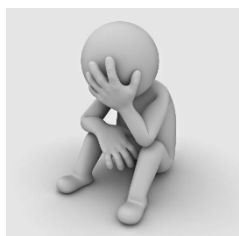
Frequency Rating

- | | |
|---|-----------|
| 1. We were patient with each other to reduce frustration | 1 2 3 4 5 |
| 2. We had a sense of humour in our conversations. | 1 2 3 4 5 |
| 3. I felt a sense of achievement if the communication strategies worked. | 1 2 3 4 5 |
| 4. I felt included in our conversations. | 1 2 3 4 5 |
| 5. I felt understood as a person | 1 2 3 4 5 |
| 6. We felt mutual respect during conversations | 1 2 3 4 5 |
| 7. I accepted we won't always get it right . | 1 2 3 4 5 |
| 8. I acknowledged when our conversation was hard . | 1 2 3 4 5 |
| 9. If I felt frustrated , (name) calmed me down . | 1 2 3 4 5 |
| 10. I could speak for myself | 1 2 3 4 5 |

Note any further thoughts and ideas expressed by the person with aphasia:

Domain 5: Generic Rating (Person with Aphasia)

Overall, how often are your conversations **together successful**?



Breakdown _____ Success

1 2 3 4 5
Not at all successful Rarely successful Sometimes successful Often successful Always Successful

Domain 5: MDCA-Relationship

Relationship questions for couples (optional) (Person with Aphasia)

Communication is important for maintaining relationships.

These questions may help you **reflect on how aphasia impacts** your **relationship** (or not) and **what steps you can take to support** each other.

How often have the following strategies helped to facilitate successful conversations with your conversation partner?

In the last month...

1 _____ 2 _____ 3 _____ 4 _____ 5
never rarely sometimes often always

Domain 5. Relationship

Frequency Rating

- | | |
|---|-----------|
| 1. I can tell my partner how I feel . | 1 2 3 4 5 |
| 2. We discuss and problem-solve situations together. | 1 2 3 4 5 |
| 3. I support my partner with empathy and understanding. | 1 2 3 4 5 |
| 4. We can still support each other in many ways. | 1 2 3 4 5 |
| 5. We can share our problems with each other. | 1 2 3 4 5 |
| 6. I listen to my partner and give them time to talk about issues. | 1 2 3 4 5 |
| 7. I can confide in my partner. | 1 2 3 4 5 |

Note any further thoughts and ideas expressed by the person with aphasia:

The Measure of Dyadic Conversation in Aphasia

MDCA- Test Version

MDCA- Partner version

Administration:

The questionnaire is designed to be administered with the primary conversation partner identified by the person with aphasia. There is a separate version for administration with the person with aphasia.

A frequency rating scale is used. The administering clinicians should describe the scale and ask the primary conversation partner to consider conversations with the person with aphasia in the last month and what has made conversations successful.

Frequency

How often have the following strategies helped to facilitate successful conversations with your conversation partner?

In the last month...

1	2	3	4	5
never	rarely	sometimes	often	always

Domain 1- Working Together- Interaction (Primary Conversation Partner)

Frequency

How often have the following strategies helped to facilitate successful conversations with your conversation partner?

In the last month...

1 _____ 2 _____ 3 _____ 4 _____ 5
never rarely sometimes often always

Domain 1- Working Together- Interaction

- 1 I clarified the topic.
- 2 I tried harder to understand if I was unsure.
- 3 I listened carefully to _____ (name)'s message.
- 4 I simplified my questions.
- 5 I focused on 1 topic at a time.
- 6 I spoke more slowly but kept an adult tone.
- 7 I used shorter sentences.
- 8 I let _____ (name) finish what they were saying.
- 9 I repeated or rephrased if _____ (name) didn't understand.
11. I asked questions to narrow down the topic.
12. I gave _____ (name) time to respond.
13. I checked we both understood.
14. We both initiated conversations with each other

Frequency Rating

1 2 3 4 5

1 2 3 4 5

1 2 3 4 5

1 2 3 4 5

1 2 3 4 5

1 2 3 4 5

1 2 3 4 5

1 2 3 4 5

1 2 3 4 5

1 2 3 4 5

1 2 3 4 5

1 2 3 4 5

1 2 3 4 5

1 2 3 4 5

1 2 3 4 5

1 2 3 4 5

Note any further thoughts and ideas expressed by the conversation partner: _____

Domain 2: Other ways of communicating- Multimodal communication (Primary Conversation Partner)

Frequency

How often have the following strategies helped to facilitate successful conversations with your conversation partner?

In the last month...

1 _____ 2 _____ 3 _____ 4 _____ 5
never rarely sometimes often always

Domain 2. Other ways of communicating

1. I gave _____ (name) my full attention.
2. I made sure _____ (name) could see me / my face.
3. I wrote keywords down as I spoke.
4. We used drawings/visuals/gestures/ to support the conversation.
5. We used technology to support the conversation.
 - a. (e.g. phone, tablet, maps, photos)

Frequency Rating				
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5

Note any further thoughts and ideas expressed by the conversation partner:

Domain 3: Familiarity and The Communication Environment- Context/Common Ground (Primary Conversation Partner)

Frequency

How often have the following strategies helped to facilitate successful conversations with your conversation partner?

In the last month...

1 _____ 2 _____ 3 _____ 4 _____ 5 _____
never rarely sometimes often always

Domain 3A: Familiarity (Context/Common Ground)

1. I asked _____'s (name) opinion on relevant life matters.
2. My knowledge of _____ (name) as a person made it easier to be on the same page.
3. My understanding of aphasia helped me to know how to support _____ (name).
4. Our shared routines, activities, memories, and background helped me to understand what _____ (name) wanted to say.

Frequency Rating
1 2 3 4 5
1 2 3 4 5
1 2 3 4 5
1 2 3 4 5

Domain 3B: Considering the communication environment-(Context/Common Ground)

5. We reduced noise and distractions.
6. We considered the time of day and avoided times when _____ (name) was fatigued.

Frequency Rating
1 2 3 4 5
1 2 3 4 5

Note any further thoughts and ideas expressed by the conversation partner:

Domain 4: Managing the impact of aphasia- Mindset and Attitude (Primary Conversation Partner)

Frequency

How often have the following strategies helped to facilitate successful conversations with your conversation partner?

In the last month...

1 _____ 2 _____ 3 _____ 4 _____ 5 _____
never rarely sometimes often always

Domain 4: Managing the impact of aphasia- Mindset and Attitude

1. I was patient to reduce frustration.
2. I recognised and acknowledged their intelligence.
3. I acknowledged we work it out together. (conversation difficulties)
4. We had a sense of humour.
5. I was aware of how my own stress can impact our conversations.
6. I helped them build confidence through encouraging conversations.

7. I acknowledged their skills and experience.

Frequency Rating
1 2 3 4 5
1 2 3 4 5
1 2 3 4 5
1 2 3 4 5
1 2 3 4 5
1 2 3 4 5

Note any further thoughts and ideas expressed by the conversation partner:

Generic Rating (Primary Conversation Partner)

1) Overall, how often are your conversations **together successful**?



Breakdown _____ Success

1

2

3

4

5

Not at all successful

Rarely successful

Sometimes successful

Often successful

Always Successful

Domain 5: MDCA-Relationship

Relationship questions for couples (optional) (Primary Conversation Partner)

Communication is important for maintaining relationships.

These questions may help you reflect on how aphasia impacts your relationship (or not) and what steps you can take to support each other.

How often have the following strategies helped to facilitate successful conversations with your conversation partner?

1 _____ 2 _____ 3 _____ 4 _____ 5 _____
never rarely sometimes often always

Domain 5: Relationship

1. I can tell my partner how I feel.
2. We discussed and problem-solved situations together.
3. I support my partner with empathy and understanding.
4. We can still support each other in many ways
5. We can share our problems with each other.
6. I listened to my partner and gave them time to talk about issues.
7. I felt I could confide in my partner.

Frequency Rating				
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5

Note any further thoughts and ideas expressed by the conversation partner:

Name/ID: _____ d.o.b.: _____ Δ: _____ Date: _____

SAQOL-39g Scoring Sheet

DURING THE PAST WEEK (Repeat as in SAQOL-39)

Item ID	How much trouble did you have (Repeat before each item or as necessary)	Couldn't do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all	Domain scores		
							Physical	Comm.	Psycho- social
SC1.	preparing food?	1	2	3	4	5			
SC4.	getting dressed?	1	2	3	4	5			
SC5.	taking a bath or shower?	1	2	3	4	5			
M1.	walking? (If respondent can't walk, circle 1 and go to question M7)	1	2	3	4	5			
M4.	keeping your balance when bending over or reaching?	1	2	3	4	5			
M6.	climbing stairs?	1	2	3	4	5			
M7.	walking without stopping to rest or using a wheelchair without stopping to rest?	1	2	3	4	5			
M8.	standing?	1	2	3	4	5			
M9.	getting out of a chair?	1	2	3	4	5			
W1.	doing daily work around the house?	1	2	3	4	5			
W2.	finishing jobs that you started?	1	2	3	4	5			
UE1.	writing or typing, <i>i.e. using your hand to write or type?</i>	1	2	3	4	5			
UE2.	putting on socks?	1	2	3	4	5			
UE4.	doing buttons?	1	2	3	4	5			
UE5.	doing a zip?	1	2	3	4	5			
UE6.	opening a jar?	1	2	3	4	5			
L2.	speaking?	1	2	3	4	5			
L3.	speaking clearly enough to use the phone?	1	2	3	4	5			
L5.	getting other people to understand you?	1	2	3	4	5			
L6.	finding the word you wanted to say?	1	2	3	4	5			
L7.	getting other people to understand you even when you repeated yourself?	1	2	3	4	5			

DURING THE PAST WEEK:

Item ID	Did you (Repeat before each item or as necessary)	Definitely yes	Mostly yes	Not sure	Mostly no	Definitely no	Physical	Comm.	Psycho- social
T4.	have to write things down to remember them, (or ask somebody else to write things down for you to remember)?	1	2	3	4	5			
T5.	find it hard to make decisions?	1	2	3	4	5			
P1.	feel irritable?	1	2	3	4	5			
P3.	feel that your personality has changed?	1	2	3	4	5			
MD2.	feel discouraged about your future?	1	2	3	4	5			
MD3.	have no interest in other people or activities?	1	2	3	4	5			
MD6.	feel withdrawn from other people?	1	2	3	4	5			
MD7.	have little confidence in yourself?	1	2	3	4	5			
E2.	feel tired most of the time?	1	2	3	4	5			
E3.	have to stop and rest often during the day?	1	2	3	4	5			
E4.	feel too tired to do what you wanted to do?	1	2	3	4	5			
FR7.	feel that you were a burden to your family?	1	2	3	4	5			
FR9.	feel that your language problems interfered with your family life?	1	2	3	4	5			
SR1.	go out less often than you would like?	1	2	3	4	5			
SR4.	do your hobbies and recreation less often than you would like?	1	2	3	4	5			
SR5.	see your friends less often than you would like?	1	2	3	4	5			
SR7.	feel that your physical condition interfered with your social life?	1	2	3	4	5			
SR8.	feel that your language problems interfered with your social life?	1	2	3	4	5			
	SAQOL-39g Mean score	Add all items and divide by 39							
	Physical score	(SC items + M items + W items + UE items) / 16							
	Communication score	(L items + FR9 + SR8) / 7							

	Psychosocial score	$(T \text{ items} + P \text{ items} + MD \text{ items} + E \text{ items} + FR7 + SR1+SR4+SR5+SR7) / 16$	
--	--------------------	---	--

1. During administration: For each item, circle number that corresponds to respondent's choice
2. To calculate domain scores: Transfer each number to shaded area in same row. Average shaded boxes per column to calculate domain scores

GENERAL HEALTH QUESTIONNAIRE

GHQ-12

Please read this carefully:

We should like to know if you have had any medical complaints, and how your health has been in general, *over the past few weeks*. Please answer ALL the questions simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those you had in the past. It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

HAVE YOU RECENTLY:

1	-	been able to concentrate on whatever you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2	-	lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
3	-	felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
4	-	felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
5	-	felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
6	-	felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
7	-	been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
8	-	been able to face up to your problems?	More so than usual	Same as usual	Less able than usual	Much less able
9	-	been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
10	-	been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
11	-	been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
12	-	been feeling reasonably happy, all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual

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Frenchay Aphasia Screening Test

Administration Form

Materials required:

Picture card with attached reading cards, pencil and paper, stop watch, or watch with second hand.

Check:

Patient is wearing spectacles, if needed. Patient can hear you adequately (raise voice if necessary).

Comprehension

Show patient card with river scene. Say; 'Look at the picture. Listen carefully to what is said and point to the things I tell you to'. Score 1 for each correctly performed. If instructions require repeating, score as error. Unprompted self-correction may be scored as correct. Score range 0-10.

Instructions

(a) River Scene

Practice item; 'Point to the river'. Do not score this item. Repeat until patient understands what is required.

1. ☐ Point to a boat
2. ☐ Point to the tallest tree
3. ☐ Point to the man and point to the dog
4. ☐ Point to the man's left leg and then to the canoe
5. ☐ Before pointing to a duck near the bridge, show me the middle hill.

(b) Shapes

Practice item; 'Point to the circle'. Repeat until patient understands task.

1. ☐ Point to the square
2. ☐ Point to the cone
3. ☐ Point to the oblong and the square
4. ☐ Point to the square, the cone and the semicircle
5. ☐ Point to the one that looks like a pyramid and the one that looks like a segment of orange

☐ Sub total /10

Expression

- (a) Show patient the river scene and say; 'Tell me as much about the picture as you can'. If the patient does not appear to understand, say; 'Name anything you can see in the picture'. Score range 0-5.

Score

- 0 ☐ Unable to name any objects intelligibly
- 1 ☐ Names 1-2 objects
- 2 ☐ Names 3-4 objects
- 3 ☐ Names 5-7 objects
- 4 ☐ Names 8 or 9 objects or uses phrases and sentences, but performance *not* normal (e.g. hesitations, inappropriate comments, etc.)
- 5 ☐ Normal – uses phrases and sentences naming 10 items

- (b) Remove picture card from view and inform patient that you are now going to attempt something a little different. Then ask him to name as many animals as he can think of in 1 minute. If patient appears doubtful, explain that you want the names of any kind of animal, wild or domestic, and not just those which many have been seen in the picture. Commence timing as soon as patient names first animal and allow 60 seconds. Score range 0-5.

Score

- 0 ☐ None named
- 1 ☐ Names 1-2
- 2 ☐ Names 3-5
- 3 ☐ Names 6-9
- 4 ☐ Names 10-14
- 5 ☐ Names 15 or more
- ☐ Sub total /10

Reading

Check that the patient is wearing correct spectacles for reading purposes. Show patient river scene and first reading card. Ask them to read the sentence to himself, not aloud, and do whatever it instructs him to do. Proceed in the same manner with the remaining four reading cards. Score range 0-5.

Score 1 for each correct.

1. ☐ Point to the dog
2. ☐ Show me the bridge
3. ☐ Point to the man standing in the barge
4. ☐ Touch the left-hand corner of the card
5. ☐ Touch the bottom of the card and then the top of it

☐ Sub total /5

Writing

Show patient river scene and say 'Please write as much as you can about what is happening in the picture'. If he does not appear to understand say 'Write anything that you can see in the picture'. If dominant hand is affected ask patient to attempt with non-dominant hand. Encourage, if patient stops prematurely. Allow a MAXIMUM of 5 minutes. Score range 0-5.

Score

- 0 ☐ Able to attempt task but does not write any intelligible or appropriate words
- 1 ☐ Writes 1 or 2 appropriate words
- 2 ☐ Writes down names of 3 objects or a phrase including 2 or 3 objects
- 3 ☐ Writes down names of 4 objects (correctly spelled), or 2 or 3 phrases including names of 4 items
- 4 ☐ Uses phrases and sentences, including names of 5 items, but not considered 'normal' performance, e.g. sentence is not integrating people and actions
- 5 ☐ Definitely normal performance, e.g. sentence integrating people and actions

☐ Sub total /5

Interpretation

The presence of aphasia is indicated if the patient scores below the following cut off points. (Referral to speech therapy for full assessment is suggested.)

Age	Raw Score
Up to 60	27
61+	25

The Communicative Participation Item Bank – General Short Form

Instructions:

The following questions describe a variety of situations in which you might need to speak to others. For each question, please mark how much your condition interferes with your participation in that situation. By “condition” we mean ALL issues that may affect how you communicate in these situations including speech conditions, any other health conditions, or features of the environment. If your speech varies, think about an AVERAGE day for your speech – not your best or your worst days.

	Not at all (3)	A little (2)	Quite a bit (1)	Very much (0)
1. Does your condition interfere with... ...talking with people you know?	☐	☐	☐	☐
2. Does your condition interfere with... ...communicating when you need to say something quickly?	☐	☐	☐	☐
3. Does your condition interfere with... ...talking with people you do NOT know?	☐	☐	☐	☐
4. Does your condition interfere with... ...communicating when you are out in your community (e.g. errands; appointments)?	☐	☐	☐	☐
5. Does your condition interfere with... ...asking questions in a conversation?	☐	☐	☐	☐
6. Does your condition interfere with... ...communicating in a small group of people?	☐	☐	☐	☐
7. Does your condition interfere with... ...having a long conversation with someone you know about a book, movie, show or sports event?	☐	☐	☐	☐
8. Does your condition interfere with... ... giving someone DETAILED information?	☐	☐	☐	☐
9. Does your condition interfere with... ...getting your turn in a fast-moving conversation?	☐	☐	☐	☐
10. Does your condition interfere with... ...trying to persuade a friend or family member to see a different point of view?	☐	☐	☐	☐

Scoring guide for the CPIB General Short Form

To score the short form, add the scores for the ten items to obtain a summary score (Not at all = 3; A little = 2; Quite a bit = 1; Very much = 0). The summary score will range from 0 – 30. High scores are more favorable, meaning that high scores indicate less interference in participation. Using the table below, the summary scores can be converted to IRT theta values (logit scale). On the logit scale, scores generally range from -3.0 to +3.0 with 0 logits representing the mean for the calibration sample. Again, high scores are preferable. The table also includes a conversion to standard T scores (mean = 50; standard deviation = 10). **VERY IMPORTANT: This score translation table is ONLY valid for the 10 item short form presented in this manuscript.** Remember that in IRT, the person score is based on the parameters of the individual items and on how the person answers the items. This scoring table has been generated using the item parameters for the ten items in this short form, and these parameters would differ for different items. A new score translation table must be created for any other combination of items.

CPIB 10-Item General Short Form Scoring Table

Summary	Theta	T score	Summary	Theta	T score
0	-2.58	24.20	16	-0.22	47.80
1	-2.18	28.20	17	-0.10	49.00
2	-1.94	30.60	18	0.03	50.30
3	-1.76	32.40	19	0.15	51.50
4	-1.60	34.00	20	0.27	52.70
5	-1.46	35.40	21	0.40	54.00
6	-1.34	36.60	22	0.53	55.30
7	-1.22	37.80	23	0.65	56.50
8	-1.10	39.00	24	0.78	57.80
9	-0.99	40.10	25	0.92	59.20
10	-0.89	41.10	26	1.06	60.60
11	-0.78	42.20	27	1.22	62.20
12	-0.67	43.30	28	1.42	64.20
13	-0.56	44.40	29	1.67	66.70
14	-0.45	45.50	30	2.10	71.00
15	-0.33	46.70			

Baylor, C., Yorkston, K., Eadie, T., Kim, J., Chung, H., & Amtmann, D. (2013). The Communicative Participation Item Bank (CPIB): Item bank calibration and development of a disorder-generic short form. *Journal of Speech Language and Hearing Research*, 56, 1190-1208.

Title of the study: Measure for Dyadic Conversation in Aphasia (MDCA): Psychometric testing

Principal Investigator: Professor Katerina Hilari

Case History Form- PWA

Responder: PWA, partner, referrer (aphasia group co-ordinator)

Participant number:

Age:

In years

Years of education:

In years

Sex:

Male, Female, Other (specify preferred term)

Ethnicity:

White, Black, Asian, Other

Marital status:

Single, married or with partner, divorced or widowed

Living arrangement:

Lives alone, lives with others (specify), assisted accommodation (specify)

Language of testing:

Primary Language:

The language most frequently used

Languages Used:

Used more than one language on a regular basis prior to aphasia? If yes, specify

Work Status:

Full time, part time, volunteer, student, not working, retired, retired due to stroke

History of conditions:

Any prior conditions that impact communication or cognition (inc., uncorrected vision and hearing)

Stroke:

Number of strokes and years post stroke

Conditions arising from stroke:

Apraxia, dysarthria, hemiparesis etc

(Name of researcher)

(date)

(Signature)

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

Case History Form- Partner

Responder: partner

Participant number:

Relationship to person with aphasia:

*Spouse/Partner, Child, Other family (specify),
Other (Specify)*

Contact with person with aphasia:

Frequency/times per week

Years of education:

In years

Sex:

Male, Female, Other (specify preferred term)

Ethnicity:

White, Black, Asian, Other

Marital status:

*Single, married or with partner, divorced or
widowed*

Living arrangement:

*Lives alone, lives with others (specify),
assisted accommodation (specify)*

Language of testing:

Primary Language:

The language most frequently used

Languages Used:

*Used more than one language on a regular
basis prior to aphasia? If yes, specify*

Work Status:

Full time, part time, volunteer, student, not working, retired, retired due to stroke

History of conditions:

Any conditions that impact communication or cognition (inc., uncorrected vision and hearing)

(Name of researcher)

(date)

(Signature)

Title of the study: **Measure for Dyadic Conversation in Aphasia (MDCA): Psychometric testing**

Principal Investigator: Professor Katerina Hilari

Questions about Communication Measures

Please think about your conversations with your partner.

1. How well does this measure capture **what you do** during your conversations with your partner?

1 _____ 10

Not well at all

Very well

2. How well does this measure capture **how you feel** during your conversations with your partner?

1 _____ 10

Not well at all

Very well

3. How **easy** was it to complete?

1 _____ 10

Not easy at all

Very easy

4. Were all the items **relevant**? (Yes/No)

5. Do you think any questions should be **removed**? (open text)

6. Was there anything missing/ to **add**? (open text)

7. Any **other thoughts** about this measure? (open text)

Ethics ETH2526-2230: Prof Katerina Hilari (Medium risk)

Date Created	25 Jun 2026
Date Submitted	25 Jun 2026
Academic Staff	Prof Katerina Hilari Prof Madeline Cruice Dr Sally McVicker Dr Abi Roper
Category	Academic Staff Academic Staff Academic Staff Academic Staff
Project	Measure for Dyadic Conversation in Aphasia (MDCA): Psychometric testing
School	School of Health & Medical Sciences
Department	Allied Health
Current status	Approved

Ethics application

Amendments

SA1) Types of modification/s

Change the design and/or methodology of the project, including changing or adding a new research method and/or research instrument

SA2) Details of modification

In this study after the screening visit, participants have two visits. In visit one the complete the following measures: MDCA, CPIB, SAQOL-39g and GHQ-12. In the second visit they only complete the MDCA again to evaluate the test-retest reliability of this new measure.

We would like also to repeat the CPIB (communication participation item bank, 10 items) in the second visit. This will allow us to also test the test-retest reliability of the CPIB. As the CPIB is only 10 items and does not take more than a few minutes to complete, the increase in burden is minimal and the total visit time will remain 20-30min.

SA3) Justify why the amendment is needed

The main aim of the study is to test the psychometric properties of the MDCA which is a new measure. However, we realised that though the CPIB is an existing measure, there is no evidence of its test-retest reliability with people with aphasia. It will be useful to collect this data, in general, but also specifically for the parent study (APT) that this study is part of, as it informs outcome measure selection for that study.

SA4) Other information

The participant information sheet for people with aphasia has been amended (track changes, so that you can see the change) to include this change.

SA5) Please upload all relevant documentation with highlighted changes

Project amendments

P1) Project title

Measure for Dyadic Conversation in Aphasia (MDCA): Psychometric testing

P2) Principal Applicant

Name

[Prof Katerina Hilari](#)

Provide a summary of the researcher's training and experience that is relevant to this research project.

Professor Hilari is an aphasia expert SLT researcher. She is an expert on outcome measurement for people with aphasia. She has led multiple aphasia projects, including psychometric studies, and has supervised multiple students in their research.

P3) Co-Applicant(s) at City

Name

[Prof Madeline Cruice](#)

Provide a summary of the researcher's training and experience that is relevant to this research project.

Aphasia expert SLT researcher. Co-leads the APT research project. She has led multiple aphasia research projects and supervised multiple students in their research.

Name

[Dr Sally McVicker](#)

Provide a summary of the researcher's training and experience that is relevant to this research project.

Aphasia expert SLT clinician and experienced aphasia practice educator and researcher. She leads Aphasia ReConnect and will assist with recruitment and data collection.

Name

[Dr Abi Roper](#)

Provide a summary of the researcher's training and experience that is relevant to this research project.

Aphasia expert SLT clinician and researcher and computer scientist. She has led many aphasia projects with tech applications. She will assist with tech aspects of the project and online data forms for data collection.

P4) External Co-Applicant(s)

Name

Dr Sharon Adjei-Nicol

Title of post

Co-investigator

Affiliation

The Marillac Neurological Care Centre

Provide details of the researcher's insurance cover.

Provide a summary of the researcher's training and experience that is relevant to this research project.

Experience aphasia researcher

Name

Natascha Ullrich

Title of post

Affiliation

Sheffield Teaching Hospitals NHS Foundation Trust

Provide details of the researcher's insurance cover.

Provide a summary of the researcher's training and experience that is relevant to this research project.

Experienced Aphasia Researcher

Name

Dr Sally McVicker

Title of post

Affiliation

Aphasia ReConnect (as well as City St George's, Univeristy of London)

Provide details of the researcher's insurance cover.

Provide a summary of the researcher's training and experience that is relevant to this research project.

Experienced aphasia researcher

Attached files

MDCA Psychometrics PIS PWA V3.docx

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.

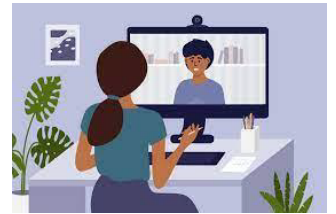
1. **Visit 1: Screening and consent.** We expect this to take up to 1 hour

- 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** and one of the other measures again. This tells us if MDCA-these communication measures gives the same result over time.
- We will ask you about **your experience** with MDCA-these measures



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**.

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