



Aphasia Partnership Training (APT)

Standard Participant Information Sheet for Interviews with Familiar Communication Partners of People with Aphasia.

1. Project Title

Aphasia Partnership Training (APT): A programme of work to co-design and evaluate the effectiveness of training a person with aphasia and their communication partner to communicate better together

2. Invitation

- You are being invited to take part in a research project - specifically to give an interview.
- The whole project aims to understand the experiences of:
 - people with post-stroke aphasia,
 - their familiar communication partners (partner/ spouse, son, daughter, brother, sister, neighbour, friend, paid carer),
 - and speech and language therapists (and related staff e.g. therapy assistant),
 - When they are receiving or delivering communication partner training in order to develop APT as a new intervention for people with aphasia and their communication partners and to develop a learning package for staff who will deliver it; and
 - On how communication impacts relationships and life.
- Please take the time to read this information carefully and discuss it with others (family/ friends/ colleagues) if you wish.
- Ask us if there is anything that is not clear or if you would like more information (see contact details below).
- Take time to decide whether or not you wish to take part - you have a minimum of 48 hours to consider whether you would like to take part.
- Thank you for reading this.

If you would like to read this Participant Information Sheet in a different language, please tell the researcher.

3. What is the project's purpose?

- Almost 40% of stroke survivors have a communication difficulty called aphasia, which can affect:
 - their ability to talk,
 - understand what is said,
 - read or write.
- This can make communicating with their family members, friends, and others difficult.
- Research shows the negative impact of not being able to communicate on people with aphasia, their familiar communication partners, and their relationships.
- We plan to develop:
 - APT as a new intervention for people with aphasia and their familiar communication partners
 - a new learning package for Speech and Language therapists working with people with aphasia and their communication partners.
- As part of developing the training we will invite people to share their experiences receiving and delivering communication partner training as part of their previous speech and language therapy.
- We will also ask people about how their communication affects them generally
- We will conduct interviews with:
 - People with post-stroke aphasia,
 - their familiar communication partners (partner/ spouse, son, daughter, brother, sister, neighbour, friend, paid carer),
 - and speech and language therapists (and related staff e.g. therapy assistant),to gather their experiences and opinions.
- We will video record the interviews and create a transcript and video clips from the interviews.
- Clips from the videos will be used to create a film which is shown to the people who design the future Aphasia Partnership Training - this will be a group of people with aphasia, familiar communication partners, and speech and language therapists
- The film will illustrate:
 - How communication impacts on people
 - How communication partner training has helped or not
 - What could be done in the future
 - What helps and hinders communication partner training to be delivered in the NHS in the UK

How to contact us

If you have any questions about the study or if you would like to take part, please contact Analisa Pais on 020 7040 3308 or 07341 492298 or email: analisa.pais@citystgeorges.ac.uk. Or contact Jean Rutter by email: jean.rutter@citystgeorges.ac.uk

4. When is the project taking place?

- The interviews will be taking place from November 2025 to March 2026.
- The large study finishes in February 2031.

5. Why have I been invited?

- You have been invited to take part because you are:
 - a person with aphasia who has received communication partner training, OR
 - a familiar communication partner of someone who has had a stroke
- You are also invited to take part if you are:
 - person with aphasia, or a familiar communication partner who has not had CPT, but would have been interested in it, and in working on their communication with others.
- We plan to interview 6-8 people with aphasia and/ or familiar communication partners, and
- We hope to include people with aphasia and familiar communication partners of:
 - different ages
 - types of aphasia
 - different relationships e.g. partner, sibling, child, friend, neighbour, paid carer
 - ethnicities
 - and first languages

6. Do I have to take part?

- It is up to you to decide whether or not to take part.
- Your participation is voluntary.
- If you do decide to take part, you will be given this Participant Information Sheet to keep (and be asked to sign a consent form or provide recorded verbal consent).
- You can choose to stop taking part in the interview at any time, without any negative consequences. You do not have to give a reason.
- If you change your mind, you have one week from the date of the interview to decide that you do not want the information you have provided to be included in the study.

If you wish to stop taking part, you can let the researcher know during the interview or by contacting

Analisa Pais on 020 7040 3308 or 07341 492298 or email:

analisa.pais@citystgeorges.ac.uk

Or contact Jean Rutter by email: jean.rutter@citystgeorges.ac.uk

Standard Participant Information Sheet, Version 3, 2.12.2025

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Please note that by choosing to participate in this research, this will not create a legally binding agreement, nor is it intended to create an employment relationship between you and City St George's, University of London.

7. If I take part, what will I have to do?

- You will be invited to take part in an interview.
- The interview will be carried out by:
 - by videocall (e.g., Zoom) or
 - in person at City St George's University of London
- The interview will last up to one hour. The interview will be video recorded so clips can be shown to the people developing the staff training.
- The researcher will ask you to provide some information about you (age, ethnic group, gender, languages spoken, etc). This information will help us to know whether we have included a diverse group of people in the interviews.
- The researcher carrying out the interview will ask you to describe–
 - Experiences of receiving communication partner training following the stroke,
 - positive and negative experiences of communication and its impact on you
- The researcher carrying out the interviews is experienced in supporting people with aphasia to communicate during interviews.

If one or more clips from your video are selected to be shown to the team designing the training, we will send them to you to look at to check you are happy with them.

8. Will I be recorded, and how will the recorded media be used?

The interview will be video recorded. How it is recorded will depend on whether the interview is conducted:

- Videocall: it will be recorded using the record function within the videocall (e.g., Zoom)
- In person: it will be recorded using a video camera
- The video recording will be watched by members of the work package 2 research team and our patient and public involvement group to identify patterns across different people's experiences.
- Clips from the recordings will be shown to the people involved in designing the training.
 - This will include:
 - People with aphasia,
 - Familiar communication partners
 - Speech and language therapists, and related staff e.g. SLT assistant
 - (approximately twelve people)

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- We would also like your permission to use clips from your video recording for wider purposes, including:
 - in the intervention and learning package we are developing,
 - and in conference presentations or teaching students
 - to raise awareness of the impact of aphasia and communication partner training.
 - This part is optional, and you can still take part even if you do not want the clips shared beyond the team designing the training.

9. What are the possible disadvantages and risks of taking part?

- In total, the interview will take up to one hour (1hr) of your time.
- Talking about your communication and speech and language therapy you have received during the interview may bring up difficult memories or experiences. In order manage this possibility:
 - You will not be asked to discuss anything you find too sensitive.
 - You can choose to not answer a question.
 - You can take a break or stop at any point during the interview.
 - You can also bring someone else for moral support if you would like.
 - You can also ask to chat to the researcher after the interview is finished.
 - If the interview brings up difficult issues you wish to discuss further, we will provide contact details for relevant support services in your area.
- As we will share the video recordings with others involved in the research and training design process it is possible that you will be identified.
- We will discuss this immediately before the interview to ensure you only provide information you are happy to share.
- We will also check if there is anything you do not want to be shared at the end of the interview.
- **If you agree** to your video being shared more widely in the intervention and learning package, conference presentations or teaching then you and the experiences that you share will be viewed by a wider audience.
- You can still take part even if you do **not** want your video to be shared more widely.

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10. What are the possible benefits of taking part?

- If you take part in an interview, you will receive a £25 voucher to thank you for your time.
- If you complete your interview at the university, your travel expenses will be reimbursed.
- Many people value the opportunity to talk about their experiences and believe that this will help others.
- Taking part will help with:
 - designing APT as a new intervention for people with aphasia and their familiar communication partners,
 - designing new training for speech and language therapists and related staff (e.g., SLT assistant, support worker) working with people with aphasia
 - and improve rehabilitation practices in speech and language therapy services ultimately enhancing patient/client experiences and outcomes.

11. Will my taking part in this project be kept confidential?

- We will share clips from the video recordings with:
 - the research team,
 - and the codesign team (mentioned above) involved in designing the training
- They will see your face and hear your voice.
- We will **not** identify you by name or include any other identifiable (personal) information with the video recording:
 - this means information like your name, your address, your phone number
- If you give permission for us to use clips from your video recording when we share the study findings more widely (for example in the intervention and/or the learning package, at conferences, or in teaching),
 - we will also **not** identify you by name or include any other identifiable (personal) information.
- All information collected will be strictly confidential and accessible only to the research team.
- Your identity will remain anonymous unless you explicitly consent to being identified.
- Your data will be securely stored.
- Data will be transferred at the earliest possible opportunity from Zoom or the video recorder onto a password protected and encrypted device (e.g., secure computer folder)
- Video-recordings will be retained for 10 years.
 - After this time, video-recordings will be electronically destroyed, following City St George's, University of London's policy.

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12. What is the legal basis for processing my personal data?

According to data protection legislation, we are required to let you know that the legal basis we are applying in order to process your personal data is that:

- 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)).
- Further information can be found in the University's Privacy Notice
<https://www.citystgeorges.ac.uk/about/governance/policies/general-privacy-note>

As we will be collecting some data that is defined in the legislation as more sensitive (information about health), we also need to let you know that we are applying the following condition in law:

- that the use of your data is necessary 'for archiving purposes in the public interest, scientific research purposes or statistical purposes' (9(2)(j)).

13. What will happen to the data collected, and the results of the research project?

- The data collected will be analysed directly from the recording by members of the research team to identify patterns across people's experiences.
- They will highlight:
 - What helps people with aphasia and their communication partners to improve their communication the most
 - How such supports could be provided as part of routine SLT services in the NHS
- The findings will be used to develop APT as a new communication partner training intervention for people with aphasia and their familiar communication partners, and will be shared in research publications and presentations.
- Your participation will be acknowledged but kept anonymous.

14. Who is organising and funding the research?

The research is funded by the National Institute for Health and Care Research through the Programme Grant for Applied Research programme. The grant number is NIHR 208121. More information is available on the internet:
<https://www.fundingawards.nihr.ac.uk/award/NIHR208121>.

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15. Who is the Data Controller?

- City St George's, University of London will act as the Data Controller for this study.
 - This means that the University is responsible for looking after your information and using it properly.
- The University of Sheffield will act as a Data Processor for this study.
 - This means the university may collect and/or access some data for this study, and collect/ access and store this in line with the requirements of City St Georges, University of London. This is supported by the Collaboration agreement.

16. Who has ethically reviewed the project?

This project has been ethically approved via the Division of Speech and Language Therapy, Proportionate Review Ethics Committee, within the School of Health and Medical Sciences, at City St George's, University of London.

The project and ethical approval has also been checked by Sheffield Teaching Hospitals NHS Foundation Trust who are the sponsor for this study.

17. What if something goes wrong and I wish to complain about the research or report a concern or incident?

- For complaints or concerns, please contact the Chief Investigator Professor Madeline Cruice (M.Cruice@citystgeorges.ac.uk) in the first instance.
- If you feel your complaint has not been handled in a satisfactory way you can contact the University's Research Governance, Ethics, and Integrity Manager (senaterec@city.ac.uk or see address below).
- If the complaint relates to how your personal data has been handled, you can find information about how to raise a complaint in the University's Privacy Notice:<https://www.citystgeorges.ac.uk/about/governance/policies/general-privacy-notice>
- If you wish to make a report of a concern relating to potential exploitation, abuse or harm resulting from your involvement in this project, please contact the project's Designated Safeguarding Contact Professor Madeline Cruice (M.Cruice@citystgeorges.ac.uk).
- If the concern or incident relates to the Designated Safeguarding Contact, or if you feel a report you have made to this Contact has not been handled in a satisfactory way, please contact the University's Research Governance, Ethics, and Integrity Manager (senaterec@city.ac.uk or see address below)

Research Governance, Ethics, and Integrity Manager

Research & Innovation Directorate
City St George's, University of London
Northampton Square
London, EC1V 0HB

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18. Contact for further information

For further information, please contact:

Analisa Pais on 02070403308 or 07341492298 or email: analisa.pais@citystgeorges.ac.uk or apt-programme@sheffield.ac.uk

Or contact Jean Rutter by email: jean.rutter@citystgeorges.ac.uk

Thank you for reading this participant information sheet. If you decide to participate, you will receive a copy of this participant information sheet and a consent form for your records.

FUNDED BY



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