





Aphasia Partnership Training

(APT)

Accessible Participant Information Sheet For People with Aphasia

Would you be interested in sharing your experiences of communicating partner training?

Your experiences will help us develop the aphasia partnership training as an intervention.

Together, we can develop an intervention for people with aphasia and their familiar communication partners.

You can take the **support** of a **family member** / **friend** / **therapist** to read and understand this form.

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



This information leaflet has 4 (four) main sections.

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A. Information about the study

1. Project title



Aphasia Partnership Training (APT):

Training people with aphasia and their familiar communication partner to communicate better together.

2. Invitation



You are being **invited** to take part in a research project called **APT**.

The project aims:



 To understand experiences of people with aphasia, who have received Communication Partner Training.



 To understand experiences of familiar communication partners of people with aphasia, who have received Communication Partner Training. We also want to understand the experiences of people with aphasia and/or their familiar communication partner who:

- have **not** had CPT
- but would have been interested in CPT, and
- would have been interested in working on their communication with others.

The project also aims:

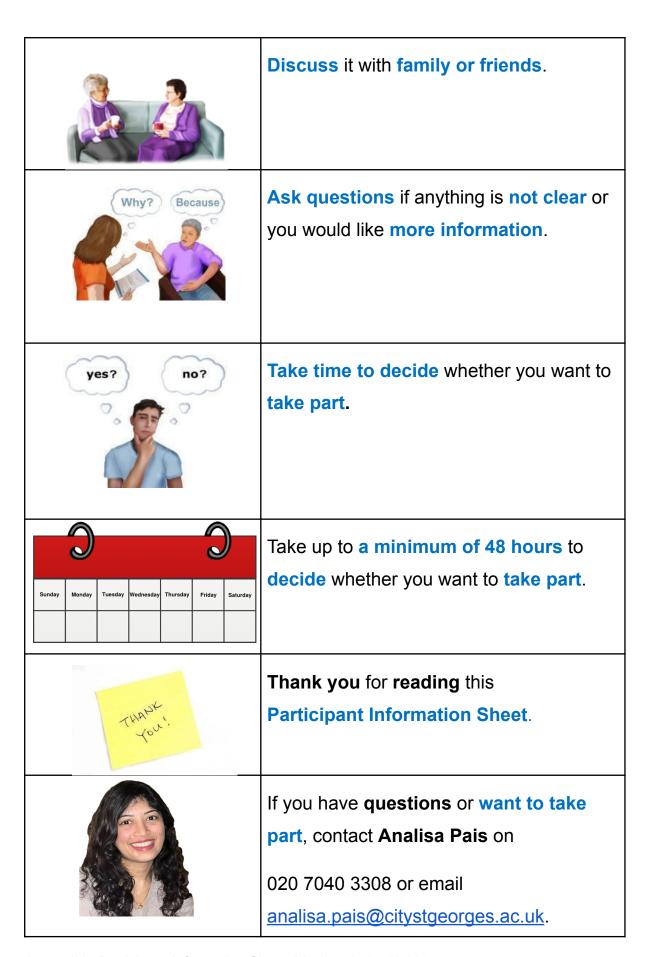
- To understand experiences of speech and language therapists, who have delivered
 Communication Partner Training.
- To develop training for people with aphasia and their familiar communication partners.



Please take time to read this

Participant Information Sheet.





3. What is the purpose of this study?



40% of stroke survivors have a **communication difficulty** called **aphasia**.

This can make it difficult to talk, understand what is said, read, and write.

This makes **communicating** with their close **families** and **friends difficult**.



Research shows the **negative impact** of **communication difficulties on relationships**.



We are developing a new CPT intervention.

It is for people with aphasia and their familiar communication partners.



We are also developing a learning package for NHS staff.

This is to help speech and language therapy (SLT) staff deliver this intervention.



We will invite people to share their experiences of receiving CPT.

We will also invite people to share their experiences of delivering CPT.

We will also ask people about how their **communication affects them** generally.



We will interview:

- people with aphasia
- familiar communication partners
 (e.g., partner/ spouse,
 children, siblings,
 neighbour, friend, paid carer)
- speech and language therapy staff.



We will gather their **experiences** and **opinions**.



We will video record these interviews.



We will also create a **transcript** and **video clips** from the **interviews**.

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Video clips will be used to create a film.



The **film** will be **shown** to a **group** of people who will **design** the training.

This will include:

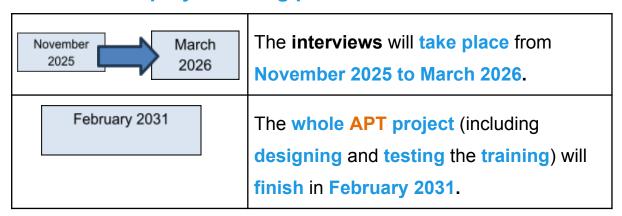
- people with aphasia,
- familiar communication partners,
- speech and language therapists.



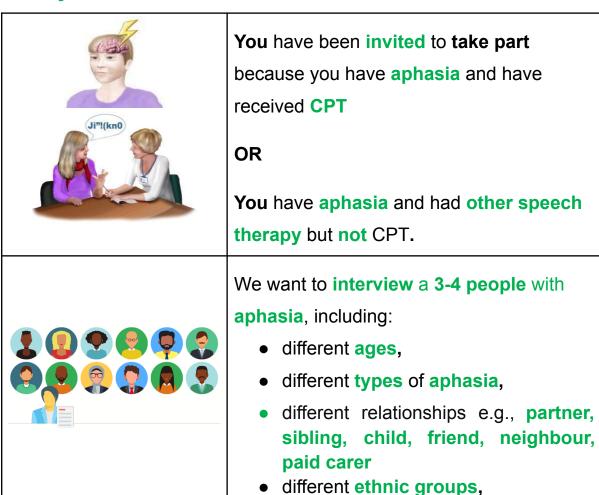
The film will illustrate:

- 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

4.When is the project taking place?



5. Why have I been invited?



people who do not speak English

as a first language.





We plan to **interview**:

3-4 familiar communication partners of people with aphasia

and **4-6 speech and language therapists** (and/or related staff e.g. SLT assistant, support worker) who are

- o different bands/ grades
- different settings e.g.,
 outpatient, domiciliary, and
 other community settings
- ethnicities
- and first languages

6. Do I have to take part?





Taking part in this research is not a legally binding agreement.

It does not mean you are employed at the City St Georges, University of London.



You can choose to stop taking part in the study at any time.



(e.g., stop the interview or say you do not want your information to be used).



If you want to **stop**, let the researcher know.



You do not have to give a reason.

There are no negative consequences.





020 7040 3308

analisa.pais@citystgeorges.ac.uk

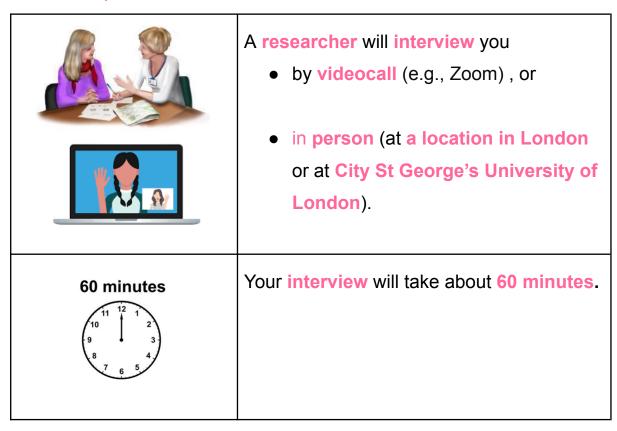


If you:

- Change your mind about taking part after the interview.
- Do not want the information you have provided to be included in the study.

You have up to **one (1) week** after the interview to decide.

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







Your interview will be video recorded.



The researcher will ask you to **provide** some **information** about:



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 will ask you about:

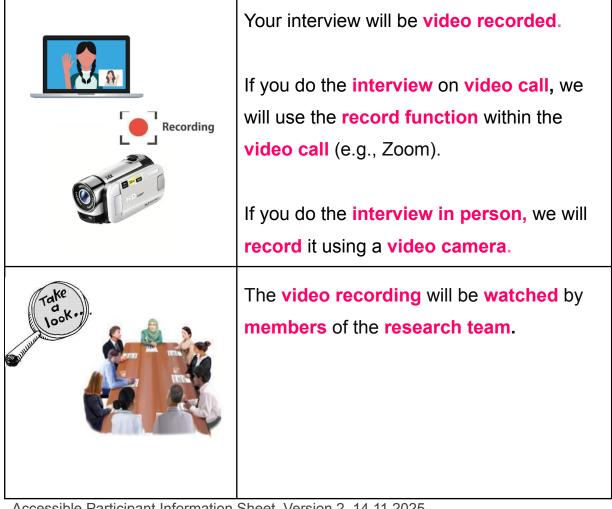
 experiences of receiving CPT (or other speech and language therapy) after your stroke



 positive and negative experiences of communication and its impact on you.



8. Will I be recorded? How will the recordings be used?





It will also be watched by our Patient and Public Involvement (PPI) Group.





The research team and the PPI group will look for patterns in people's experiences of CPT.









We will show **clips** from the **recordings** to the people designing the training.







This group will include:

- People with aphasia,
- Familiar communication partners, and
- Speech NHS Language and therapy Staff.

There will be around twelve (12) people in this group.



We might want to **use clips** from your **video** in **more ways**:

- in the training programme we develop
- in conference presentations and teaching students to raise awareness of the impact of communication disorders

This is **optional**. It is **your choice**.

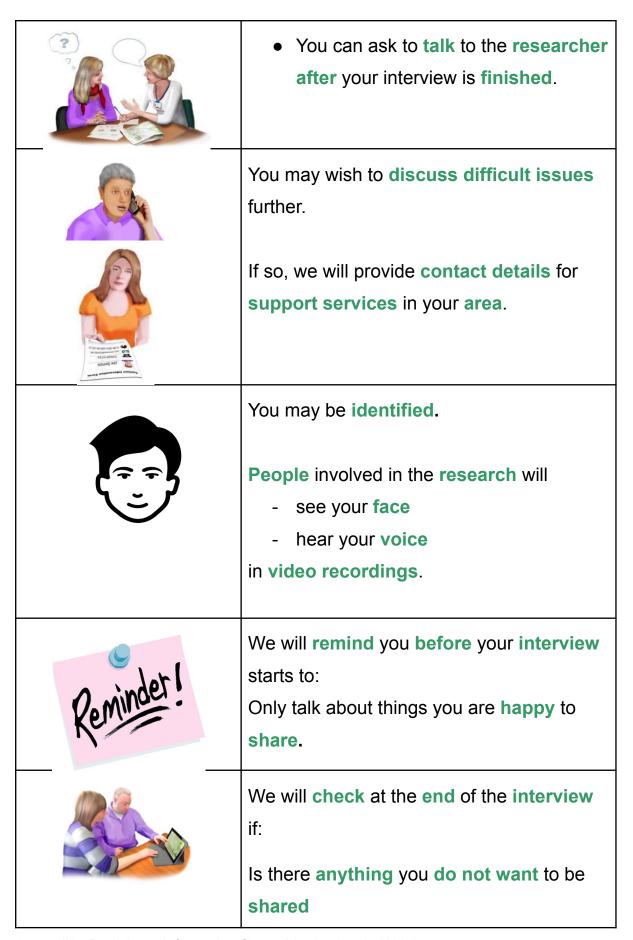
You can still take part in this study even if you do not want clips to be shared beyond the team designing the training.

B. Risks and Benefits

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

60 minutes 11 12 1 10 2 9 3 8 4	Your interview will take about 60 minutes of your time.
	During the interview, we will be talking about the CPT you received (or would have been interested in getting). This may bring up difficult memories or experiences.
STOP	 You do not have to discuss anything you find too sensitive or difficult. You can choose to not answer a question. You can take a break or stop at any time during your interview.
	You can bring someone else for support.

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Your video will be shared with a wider audience if you agree to clips being used:

- in the intervention
- in the **learning** package
- in conference presentations
- in teaching students

You can still take part even if you do not want your video to be shared more widely.

10. What are the possible benefits of taking part?





If you take part in an interview, you will receive a £25 voucher from:

- Love2Shop or
- Amazon.

This voucher is to thank you for your time





Your **travel expenses** will be **paid** if you **travel** to:

City St Georges, University of **London** for your **interview**.



The interview gives you an **opportunity** to **talk** about your **experiences of receiving CPT** (or being interested in this).

Taking part in an interview will help with:



- designing new communication intervention for
 - people with aphasia and
 - their familiar communication partners



 designing new learning package for NHS SLT staff who will deliver this intervention



- people with aphasia,
- and their familiar
 communication partners



C. Confidentiality, data management, and ethics

11.Will my information be kept confidential?

	ormation be kept confidential:
8 4 2-	We will share clips from the video
	recordings with the research team and
The state of the s	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 if you are
	happy for us to use clips from your video
Lesson 1	more widely:
	• in the intervention
	in the learning package
Towith (in conference presentations
J.SINIUI	and in teaching .
e 🚇 s	Only the research team will be able to
	access your personal information (that is
	your name, address, etc).
	All the information about you will be
	stored securely.

	Your video will be moved from the video recorder to a password protected device (e.g. computer) as soon as possible. Your data will be moved to and stored on a secure computer drive at City St
Recording	Georges, University of London. Video recordings will be kept for 10 years.
DESTROYED	After this time, video recordings will be electronically destroyed, following City St Georges, University of London's policy.

12. What is the legal basis for processing my personal data? In this section we have to use some legal words and phrases.

We have included a **brief explanation** of **what it means**.



According to data protection legislation, we are required to **inform you** 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)).



This means City St Georges University of London will keep your data because we can learn something very useful from it.

As we will be **collecting some data** that is defined in the legislation as 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)).

Further information can be found in the University's Privacy Notice

https://www.citystgeorges.ac.uk/about/gover nance/policies/general-privacy-notice

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This means City St Georges University of London is keeping your data for research purposes.

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

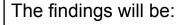


The **research team** will **watch** the **videos** of the **interviews**.



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





 used to develop APT as a new communication partner training intervention for people with aphasia and their familiar communication partners.



 shared in research publications and presentations.



Your participation will be acknowledged but we will not use your name.

14. Who is organising and funding the research?



The National Institute for Health and Care Research is funding this research.

They are funding it through the **Programme Grant** for Applied Research programme.

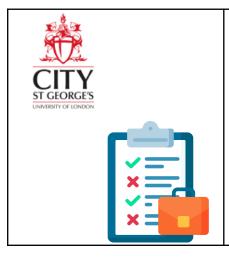
The grant number is NIHR 208121.



More information about the study can be found here:

https://www.fundingawards.nihr.ac.uk/award/NIHR2 08121

15. Who is the Data Controller?



City St Georges, University of London is the Data Controller.

They are **responsible for**:

- looking after your information, and
- · making sure that it is used properly.





The University of Sheffield is a Data Processor. This means that:

- They may collect some data for this study.
- They may also **store** the data.
- They will do this in line with the rules from 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** by:

The School of Health and Medical Sciences, Research Ethics Committee, at City St Georges, 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.

D. Grievances and contact information

17. What if something goes wrong and I wish to complain about the research?



If you would like to **complain** or if you are **concerned**, please contact:



Professor Madeline Cruice

M.Cruice@citystgeorges.ac.uk
(Study lead)



If you are **not happy** with how your **complaint** has been **handled**, please contact:



The 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



If you feel that **your data** was **not handled correctly**, you can find information about how to complain here:

https://www.citystgeorges.ac.uk/about/governance/policies/general-privacy-notice





If you wish to **report** a **concern** relating to:

potential exploitation, abuse or harm due to your involvement in this project,

Then, please contact the project's **Designated Safeguarding Contact**:

Madeline Cruice

M.Cruice@citystgeorges.ac.uk



If you feel a report you have made to this Contact has **not been handled** in a **satisfactory way**, please contact:

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

18. Contact for further information



Analisa Pais
020 7040 3038

analisa.pais@citystgeorges.ac.uk
apt@citystgeorges.ac.uk
City St Georges, University of London

Thank you for reading this Participant Information Sheet.

If you decide to **participate**, we will give you a **copy** of this **Participant Information Sheet** and a **consent form** to **keep**.







Images credit: Gill Pearl, Speakeasy-aphasia

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