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**	3 - 16
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A. Information about the study
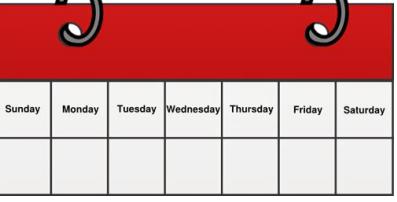
1. Project title

	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**.

	Discuss it with **family or friends**.
	Ask questions if anything is **not clear** or you would like **more information**.
	Take time to decide whether you want to **take part**.
	Take up to **a minimum of 48 hours** to **decide** whether you want to **take part**.
	Thank you for **reading** this **Participant Information Sheet**.
	If you have **questions** or **want to take part**, 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

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**.

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?

November 2025 → March 2026	The **interviews** will **take place** from **November 2025 to March 2026**.
February 2031	The **whole APT project** (including **designing** and **testing** the **training**) will **finish** in **February 2031**.

5. Why have I been invited?

	You have been **invited** to **take part** because you have **aphasia** and have received **CPT** **OR** **You** have **aphasia** and had **other speech therapy** but **not** CPT.
	We want to **interview** a **3-4 people** with **aphasia**, including: ● different **ages**, ● different **types** of **aphasia**, ● different relationships e.g., **partner, sibling, child, friend, neighbour, paid carer** ● different **ethnic groups**, ● 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

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

6. Do I have to take part?

	It is up to **you** to **decide** if you **want** to **take part**.
	Your **participation** is **voluntary**.
	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**.

If you **want** to **withdraw**, **contact** the **researcher**:
Analisa Pais
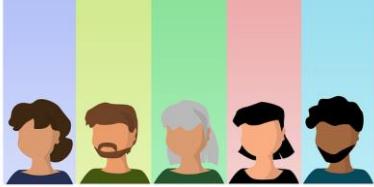
or

Jean Rutter

	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?**
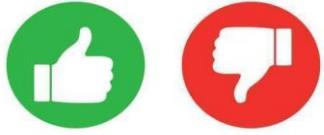
	A **researcher** will **interview** you
	● by **videocall** (e.g., Zoom) , or
	● in **person** (at **a location in London** or at **City St George's University of London**).
	Your **interview** will take about **60 minutes**.

	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.

	The **researchers** are **experienced** in **supporting people with aphasia** to **communicate** during **interviews**.
	We will **select clips** from **your video**. We will **show** you the **clips**. We will **check if you** are **happy** with them.

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

	Your interview will be **video recorded.** If you do the **interview** on **video call,** we will use the **record function** within the **video call** (e.g., Zoom). If you do the **interview in person,** we will **record** it using a **video camera.**
	The **video recording** will be **watched** by **members** of the **research team.**

	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 **NHS Speech and Language therapy Staff**. There will be around **twelve (12) people** in this **group**.

We might want to **use clips** from your **video** in **more ways**:
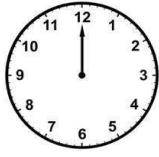
- in the **training** programme we **develop**
- in **conference presentations** and **teaching students** to **raise awareness** of the **impact** of **communication disorders**
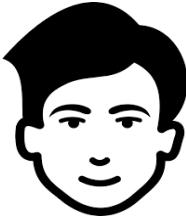
This is **optional**. It is **your choice**.

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	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	If this happens: ● 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**.
	● You can ask to **talk** to the **researcher after** your interview is **finished**.
	You may wish to **discuss difficult issues** further. If so, we will provide **contact details** for **support services** in your **area**.

	You may be **identified.**
	
	People involved in the **research** will
	  - see your **face**
	  - hear your **voice**
	in **video recordings**.

	We will **remind** you **before** your **interview** starts to: Only talk about things you are **happy** to **share**.
	We will **check** at the **end** of the **interview** if: Is there **anything** you **do not want** to be **shared**

	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**.

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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** 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 George**s, 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
	
	● thereby, **improve communication between**
	   - **people with aphasia**,
	   - and their **familiar communication partners**

B. Confidentiality, data management, and ethics

11.Will my information be kept confidential?

	We will **share clips** from the **video recordings** with the **research team** and 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 more widely:** ● in the **intervention** ● in the **learning** package ● in **conference presentations** ● and in **teaching.**

	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 Georges, University of London.**
	Video recordings will be **kept** for **10 years**.
	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 **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)).

	Further information can be found in the University's Privacy Notice https://www.citystgeorges.ac.uk/about/governance/policies/general-privacy-notice 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**?
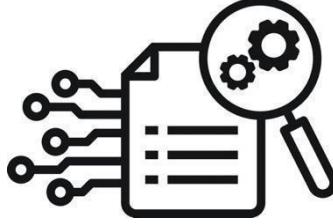
	The **research team** will **watch** the **videos** of the **interviews.**
	They will highlight
	- **what** helps **people with aphasia** and their **communication partners** to **improve** their **communication** the most
	- **How** such **supports** could be provided as part of **routine SLT** services in the NHS

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	The findings will be:
	• 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/NIHR208121

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 or 07341492298 analisa.pais@citystgeorges.ac.uk OR apt-programme@sheffield.ac.uk City St Georges, University of London
	Jean Rutter Jean.Rutter@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