

Emotional and language recovery in aphasia (ELLA study)

Information sheet – for person with aphasia

You are invited to take part in a **research** study.



Before you decide, we want you to understand:

- The **aims** of the research
- What we will ask **you to do**

Please **read** this sheet carefully. Please ask **questions**.

Discuss it with other people. **Take your time** to decide.

Who is doing the research?



The person leading the project is **Sarah** Northcott.

Sarah is a Speech and Language Therapist.

You can contact Sarah:

Email: sarah.northcott@citystgeorges.ac.uk

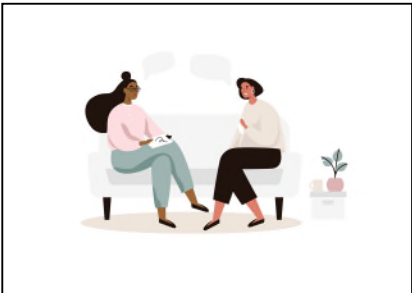
Telephone: 020 7 040 3186

The research is funded by National Institute for Health Research (Research for Patient Benefit, NIHR 207125)

The sponsor of this research is East London NHS Foundation Trust (Ref: N-2658)

Reference: Information Sheet Version 3.0 (date 2nd Oct 2025); IRAS number: 334237

What is the research about?

 	It can be difficult to talk after a stroke. This is called aphasia. People know what they want to say, but sometimes they can't say it. Sometimes this can make people feel sad and lose confidence.
	We have developed a new therapy It is called the ELLA therapy (Emotional and Language recovery in Aphasia). We want to see if ELLA therapy helps people with: • Saying words • Having conversations • Feeling confident to take part in things We want to compare this new therapy with standard NHS therapy

Why me?

	You have had a stroke You have aphasia (difficulties talking) We are inviting 42 people to take part
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Do I have to take part?

	You can decide Taking part is voluntary You do not have to take part
	You can change your mind You can stop at any time You don't have to give a reason You don't have to answer all the questions
	Stopping will not affect your normal care If you don't want to take part you will still receive your normal care

Can I withdraw from the study?

	Yes – you can decide to withdraw (stop taking part) You may decide the new therapy is not right for you – that's fine, you can stop. You can talk it over with your speech therapist.
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Is the research ethical?

	An ethics committee decides if research can happen They say that it is ethical This study has been approved by [Research Ethics Committee]
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What is involved?

	Questionnaires We will invite everyone to complete questionnaires We will ask you questions about - How you are feeling - How you are getting on with things We will also complete a short language assessment
	Some people will also do ✓ ELLA therapy ✓ Interview – your views about the therapy

What happens if I take part?

 	42 people will take part Group 1 (normal care): about 21 people Group 2 (ELLA therapy): about 21 people The computer decides This is like flipping a coin Both groups are important Both groups receive normal NHS care Both groups do the questionnaires
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How long will it take?

	You will be in the project for about 6 months This is the same for both groups
	Each research visit takes about one hour Therapy sessions also take up to an hour or less

What happens if I am in **Group 1 (normal care)**?

	Researcher visits you – questionnaires
	Computer says Group 1 – normal care
	Standard NHS care
	Researcher visits you 3 months' later – questionnaires
	3-month break
	Researcher visits you – questionnaires (final visit) & thank you

What happens if I am in **Group 2 (ELLA therapy)**?

	Researcher visits you – questionnaires
	Computer says Group 2 – ELLA therapy
	ELLA therapy sessions (<i>instead of</i> NHS standard language therapy – you will still receive all other NHS care)
	Researcher visits you 3 months' later – questionnaires
	3-month break
	Researcher visits you – questionnaires Researcher visits you – interview (final visit) & thank you

What is ELLA therapy?

	2 or 3 therapy sessions a week for about 7 to 10 weeks (about 20 hours in total) - your speech & language therapist will check your preferences Your speech & language therapist will ask about what's important to you The therapy may help you to say words, have conversations, build confidence You may do some sessions with a student Speech and Language Therapist or assistant therapist. They will be supported by an experienced therapist.
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Where will the research happen?

 	Research visits (questionnaires) You can choose, for example: We can visit you in your home We can see you online
	Therapy sessions Where you normally have NHS speech and language therapy (e.g., clinic, home, online)

Will the project help me?

	You may enjoy taking part You may find it interesting to talk about your stroke and your life in the research visits It may help other people with aphasia in the future
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What might be difficult about taking part?

	There are no medical risks or dangers – and you will still receive NHS care You will give up some time If you feel sad we will support you If you feel tired you can take a break or keep sessions short You can stop at any time
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Will I get paid?

	You will not get paid for taking part in the research
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Recordings

	With your permission we will audio record some sessions
	With your permission we will video some sessions
	If we interview you – we will transcribe the interview afterwards (write down what you say) Computer software will help us
	The recordings will be kept safe Only the research and clinical team will have access to the recordings If we want to share video clips in training and presentations we will always ask you first

What will happen to the results?

	We will give you a summary of the results of the research We can give this to you by December 2027
	We will share the results with professional bodies and others (present them, publish them)
	The results will not use your name. The results may include what you said (quotes) but not who said it

Is it confidential?

	We will keep the information about you safe Only the researchers will see your information. We may share your information with students in the research team We will remove your name and personal details from information we collect All data will be destroyed after 10 years
	We may share information with other researchers – we will de-identify it first For example, we may share what you say with other aphasia researchers We will take out your name and personal details
	If the researcher is worried about your mental or physical health, they may want to talk to your stroke team or your GP. They will always discuss this with you first

Your data

	We will only use information that we need for the research study Everyone involved in this study will keep your data safe and secure We will also follow all privacy rules There is more information at the end of this leaflet
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What next?



If you give **consent**, we will make a time to **visit you**

We will complete the questionnaires – then we will tell you if you are **Group 1 (normal care)** or **Group 2 (ELLA therapy)**

Want to talk to someone about the study?



For further information, or if you want to **talk** to someone, the **main researcher** is:

Dr Sarah Northcott
Senior Lecturer, City St George's, University of London
Sarah.Northcott@city.ac.uk
020 7040 3186



If you want to contact **someone else**, you can talk to:
Professor **Katerina Hilari**
City St George's, University of London
K.Hilari@city.ac.uk
020 7 040 4660



What if there is a problem?

If you are not happy, please do **tell Dr Sarah Northcott**, the lead researcher: Sarah.Northcott@city.ac.uk
020 7040 3186

To **complain** about the study, please contact:



Patient Advice and Liaison Service (PALS):
Tel: 0800 085 8354;
Email: elft.complaints@nhs.net;
Address: The Complaints and PALS Manager,
FREEPOST RTXT-HJLG-XEBE
Trust Headquarters,
East London NHS Foundation Trust
Robert Dolan House, Trust Headquarters
9 Alie Street, London E1 8DE

Thank you for taking the time to read this information sheet

More information about your data

How will we use information about you?

We will need to **use information from** you for this research project. This information will include **your name, contact details** and a few other details (e.g., your sex, ethnicity, languages spoken, age, years of clinical experience). People will use this information **to do the research** or to check your records to make sure that the research is being **done properly**.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a **code number** instead.

East London NHS Foundation Health Trust is the sponsor, and is **responsible for looking after your information**. We will share your information related to this project with City St George's, University of London. We will keep all information about you **safe and secure** by storing it on the secure City St George's University OneDrive or in locked filing cabinets. We will **remove your personal details** and all potentially identifying information from data.

International transfers

Your personal data will not be shared outside the UK.

How will we use information about you after the study ends?

Once we have finished the study, we will **keep some of the data** so we can check the results. We will write our reports in a way that **no-one can work out that you took part** in the study. We will keep your study data for a **maximum of 10 years**. The study data will then be **fully anonymised** and securely archived or destroyed. Fully anonymised quantitative datasets will be deposited in repositories.

What are your choices about how your 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
- you have the right to ask us to **access, remove, change or delete data** we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

Where can you find out more about how your information is used?

You can **find out more** about how we use your information:

- the leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team, for example, sending an email to: sarah.northcott@city.ac.uk or ringing Sarah on 020 7 040 3186

Alternatively, you can ask **Chris Kitchener**, the ELFT Data Protection Officer:

- by sending an email to elft.dpo@nhs.net or by ringing 0207 655 4110

Helpful numbers

	The Stroke Association, UK's leading stroke charity https://www.stroke.org.uk/	0303 3033 100 (Mon-Fri, 9am – 5pm) helpline@stroke.org.uk
	Aphasia Re-Connect Offering support, groups, befriending https://aphasiareconnect.org/	07885 288943 info@aphasiareconnect.org
	Different Strokes, for younger stroke survivors https://differentstrokes.co.uk/	0345 130 7172 or 01908 317 618 info@differentstrokes.co.uk
	Age UK https://www.ageuk.org.uk/	0800 678 1602 8am-7pm, every day
	Carers UK https://www.carersuk.org/	0808 808 7777 (Mon-Fri, 10am- 6pm) advice@carersuk.org
	Samaritans Confidential listening https://www.samaritans.org/	116 123 (all day, all year) jo@samaritans.org
	Saneline – national, out-of-hours mental health helpline. Emotional support https://www.sane.org.uk/	0300 304 7000 (4pm to 10pm) support@sane.org.uk
	NHS non-emergency medical helpline	111 (free-to-call, 24 hours every day)