

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 1.0 (date 18th July 2025); IRAS number: 334237




What is the research about?

 	<p>It can be difficult to talk after a stroke.</p> <p>This is called aphasia. People know what they want to say, but sometimes they can't say it.</p> <p>Sometimes this can make people feel sad and lose confidence.</p>
	<p>We have developed a new therapy</p> <p>It is called the ELLA therapy (Emotional and Language recovery in Aphasia).</p> <p>We want to see if ELLA therapy helps people with:</p> <ul style="list-style-type: none">• Saying words• Having conversations• Feeling confident to take part in things <p>We want to compare this new therapy with standard NHS therapy</p>


Why me?

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

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



Is the research ethical?

	<p>An ethics committee decides if research can happen</p> <p>They say that it is ethical</p> <p>This study has been approved by [Research Ethics Committee]</p>
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Will I get paid?

	<p>You will not get paid for taking part in the research</p>
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What is involved?

	<p>Questionnaires</p> <p>We will invite everyone to complete questionnaires</p> <p>We will ask you questions about</p> <ul style="list-style-type: none">How you are feelingHow you are getting on with things <p>We will also complete a short language assessment</p>
	<p>Some people will also do</p> <ul style="list-style-type: none">✓ ELLA therapy✓ Interview – your views about the therapy

What happens if I take part?

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

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


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

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

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

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


What is ELLA therapy?

	<p>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</p> <p>Your speech & language therapist will ask about what's important to you</p> <p>The therapy may help you to say words, have conversations, build confidence</p> <p>You may do some sessions with a student Speech and Language Therapist or assistant therapist. They will be supported by an experienced therapist.</p>
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Where will the research happen?

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




Will the project help me?

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

	<p>There are no medical risks or dangers – and you will still receive NHS care</p> <p>You will give up some time</p> <p>If you feel sad we will support you</p> <p>If you feel tired you can take a break or keep sessions short</p> <p>You can stop at any time</p>
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Recordings

	<p>With your permission we will audio record some sessions</p>
	<p>With your permission we will video some sessions</p>
	<p>The recordings will be kept safe</p> <p>Only the research and clinical team will have access to the recordings</p> <p>If we want to share video clips in training and presentations we will always ask you first</p>

Is it confidential?

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

What will happen to the results?

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

More information about my data

<p>The Data Controller for this study is East London NHS Foundation Trust (ELFT).</p> <p>The Data Controller is responsible for looking after your information and using it properly.</p> <p>Your right to access, change or move your information are limited: we need to manage your information in a specific way so the research is reliable and accurate.</p> <p>To safeguard your rights, we will use the minimum personal-identifiable information possible.</p> <p>The researchers will use your name and contact details to contact you about the research study as necessary.</p>
<p>Withdrawing your data</p> <p>You may withdraw your data before it has been de-identified.</p> <p>After this, you will no longer be able to withdraw your data</p>
<p>You can find out more about how we use your information</p> <p>Leaflet available at: www.hra.nhs.uk/patientdataandresearch</p> <p>You can ask one of the research team (sarah.northcott@city.ac.uk; 020 7 040 3186)</p> <p>You can also ask Chris Kitchener, the ELFT Data Protection Officer: by sending an email to elft.dpo@nhs.net by ringing 0207 655 4110</p>

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

Helpful numbers

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