

Core outcome set for dysarthria after stroke

Easy access participant information sheet: V2 (17/03/2022)

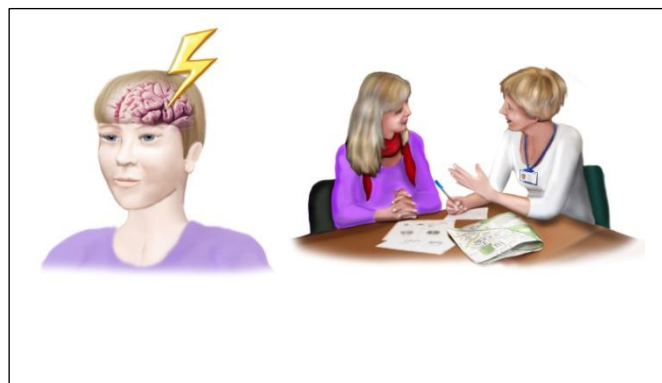
UOM rec ref: 2022-13303-22550; UQ rec ref 2022/HE000641

**For participants who have aphasia as well as dysarthria
or prefer easy access information.**

Lead researcher Dr Claire Mitchell
Claire.mitchell@manchester.ac.uk

What is this study?

Agreement on what to measure in speech recovery after stroke



If your speech sounds slurred or different after a stroke you may have or have had **dysarthria**.

We want to get agreement about what is most important to stroke survivors about their speech after stroke.

Why do we want to do this research?



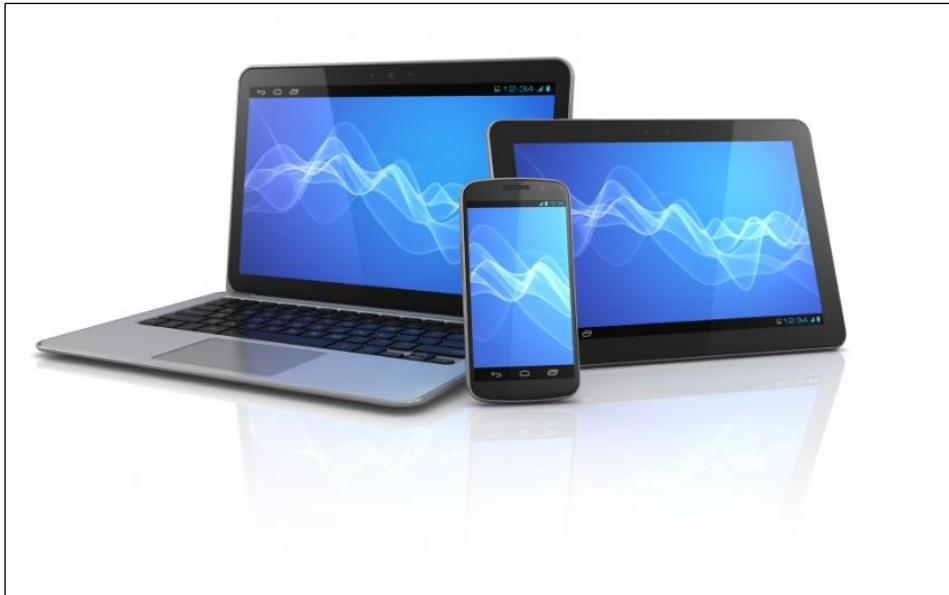
- So that Research studies **all measure** the same things which helps us to understand what treatment will work.



- By knowing what is important to stroke survivors, speech and language therapists can **all use the same measures**

We will do this using a survey online using a connected device.

We will do this using a survey online using a connected device.



We will ask you questions and you decide how important it is to you.

	Questions:	1	2	3	4	5	6	7	8	9
		Least important  most important								
1	How important is it to you to speak with a strong sounding voice?									

What else will we do?

We will also have one online meeting to discuss the answers everyone has given in the survey and make sure everyone agrees

We will have a 2nd online meeting to discuss what tests could be used with what we have agreed should be measured



2. Do I have to take part?

No it is up to you to decide whether or not you want to take part



3. What will be involved if I do agree to take part?

We will email you and ask you to complete two online surveys a couple of months apart – each one will last about 30-45 minutes



We will email you and ask if you can join either of our two zoom meetings which will last one hour each.



At the end we will have agreed what aspects of speech should be measured after stroke and how we measure them.

4. Data privacy information:

The law says that we must have a **legal basis**

to collect your data



The University of Manchester is the **data controller** for this research.

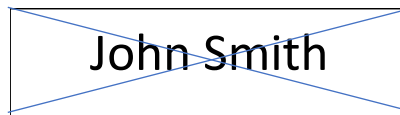
This means the University of Manchester is **responsible** for making sure your data is:

1) Kept securely and confidentially



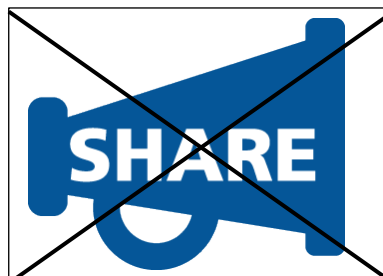
2) Only used in the way the researchers tell you it will be used

Your data will be anonymised as soon as possible. This means any personal information which could identify you will be removed.



The data remaining will be kept for 5-10 years.

Your anonymised data will not be shared with other researchers.

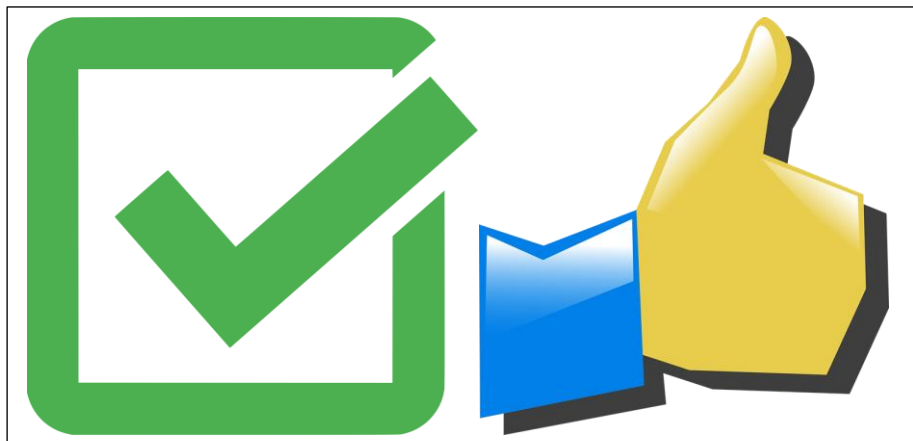


You can learn more about your data privacy by reading [The University privacy notice](#)

4. How do I get involved?

Survey: If you want to get involved you can carry out the online survey and give your consent at the start

Meetings for agreement: complete the consent form you are sent



If you want to get involved but need support then email or ring

Claire.mitchell@manchester.ac.uk

01612753442