



## ICTUS Research Study

Improving **C**are, research **T**ranslation, and treatment **U**sage in **S**troke  
Information for people who have experienced a stroke



Please read this **Information Sheet and Consent Form**.

It tells you about the study in an easy way for people with communication and cognitive challenges.

**You can then decide if you want to take part – YES or NO**

### What is this study about?

**We want your opinion on stroke care in Australia** for a research study.

**We want to hear your opinions and ideas** on how to improve stroke care.

**We want to understand how different types of health professionals can help support** care for stroke survivors like you.

This will help us to design **better resources and health services**. We plan to test to your ideas in **research studies**.





## Who can participate in this study?

**Any person who has had a stroke can take part in this study to share their opinions and ideas.**

We aim to include people from all over Australia.

**We want to hear from a range of people with different experiences.** There are no right or wrong opinions or ideas in this study.

**We will ask opinions from stroke survivors,** carers, health professionals, and stroke organisations. We will use everyone's ideas to develop future studies to test new services or new resources.

Ask questions if you don't understand or want to know more about this study. You can talk about it with family, a friend or your doctor.





## What does this study involve?

**We will interview you two (2) times.**

In **Interview 1** we will ask about your opinions and ideas about improving stroke care.

In **Interview 2 (about 1 month later - optional)** we will show you the way we plan to use your ideas in future studies to improve stroke care. We will ask whether you like this plan.

In future, we will also ask if you would like to be involved as a Consumer-Researcher in future studies.

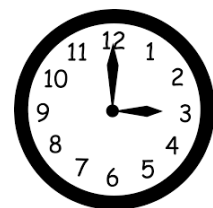
You can say YES or NO to being involved in any part of the research, at any time.

**You can choose to be interviewed:**

- by **telephone** (about 1 hour)
- **online (Zoom)** on your **own** (about 1 hour)
- **online (Zoom)** in a **small group** (about 2 hours)
- **in person** (various locations) (about 1-2 hours)

Your **carer can support** you during the interview.

It will take **about up to 2 hours** of your time, with breaks to eat, drink, rest, stretch, and toilet.





## How else can I participate?

If you do not want to be interviewed you can share your opinions and ideas by writing comments:

- in an online form – click here <https://redcap.link/ICTUS>
- on a paper form

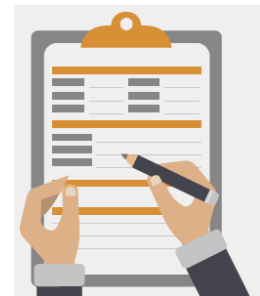
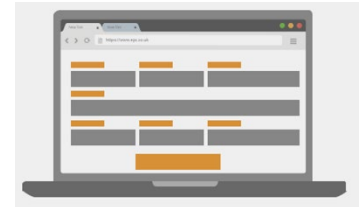
You can contact us for a paper form or for help in filling out the online form:

Email us: [poststrokestudy@uts.edu.au](mailto:poststrokestudy@uts.edu.au)

Phone us: 0407 584 635

You can write as much or little as you like.

Your comments are confidential – they will be stored securely by our team. All personal information will be removed from your form or email.





## Are there any cost or risks in participating?

It will not cost you anything to be in this study.

You will receive a \$50 gift card for your time in participating in each interview.

We hope that sharing your opinions and ideas will be a positive experience.

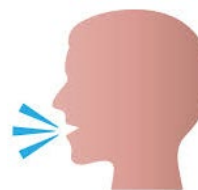
But, there is a risk that **you may feel upset or embarrassed** sharing your experiences, opinions and ideas about stroke care, especially with other people.

**We want everyone to freely and safely share their opinions. We will also maintain your privacy.**

If you feel upset or embarrassed you can:

- tell us how you feel
- not answer questions that make you upset
- stop immediately, take a break, and continue only when you want to. Or you can withdraw entirely.

We will offer you support if you feel upset or embarrassed.





## What do I have to do if I want to participate?

Participation is voluntary. **You can say YES or NO to taking part in this research study.**



**YES**



**NO**

**If you want to say YES and take part in this study, you will be asked to provide your consent to show that you:**

- understand what you have read
- consent to take part in the research
- consent to sharing your opinions and ideas in an interview or on a form



**You can say YES or NO to taking part by** telling us in words, pointing on the consent form, nodding your head when we ask, clicking the box on the online form, or signing the consent form.



You can change your mind at any time by contacting us:

Email us: [poststrokestudy@uts.edu.au](mailto:poststrokestudy@uts.edu.au)

Phone us: 0407 584 635







## What will happen to my information?

**We will voice-record interviews** to help us write notes later. The recording will stay private until we delete it at the end of the study.



We will store your information securely for at least 7 years. Only the research team can see the information unless required by law. If you withdraw from the study, any information that you provide will be safely retained.



The information you provide will remain confidential.

**We will remove all personal information from the study files. We WILL NOT use your name or identify you in any way.** You have the right to access and check your information. We will send you a copy of the project report.



This study has been approved by the Human Research Ethics Committee of the University of Technology Sydney.



If you are concerned about how this study is being conducted or wish to make a complaint you can:

- phone the Ethics Secretariat on (02) 9514 2478
- email [Research.Ethics@uts.edu.au](mailto:Research.Ethics@uts.edu.au)





## Where can I get more information and ask questions?

You can contact the study team if you have questions or concerns:

**Mr Esminio Rivera** (Research Assistant) can discuss the study with you.

Phone: 0407 584 635

Email: [Esminiol.Rivera@uts.edu.au](mailto:Esminiol.Rivera@uts.edu.au)

**Ms Beata Bajorek** (Study Team Leader) can discuss the study with you.

Email: [Beata.Bajorek@uts.edu.au](mailto:Beata.Bajorek@uts.edu.au)

Members of our research team may also contact you to answer specific questions. Our team includes:

Psychologists (mental health)

Pharmacists (medications)

Physiotherapists (movement)

Orthoptists (eye health)

Speech Pathologists (speech, swallowing)

Genetic Counsellors (inherited conditions)

