



ICTUS Research Study

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

WHAT IS THIS RESEARCH ABOUT?

This study will ask people for practical ideas on how to make stroke care better.

We want to know your:

- opinions about gaps in stroke care, from your own experience
- ideas on ways to close these gaps in care
- thoughts on how allied health professionals can help improve stroke care

Allied health professionals include:

Psychologists (mental health)

Pharmacists (medications)

Physiotherapists (movement)

Orthoptists (eye health)

Speech Pathologists (speech, swallowing)

Genetic Counsellors (inherited conditions)

Your opinions will lead to research studies where we can test ideas to improve stroke care.

WHO IS DOING THE RESEARCH?

We are a team of clinical academics and allied health professionals from University of Technology Sydney working in stroke care:

Beata Bajorek

Michelle Courtney-Harris

Amanda French

Chris Jacobs

David Kennedy

Ian Kneebone

Alana McCambridge

Emma Power

Camilla Quel De Oliveira

Peter Stubbs

Esminio Rivera

Clinical Pharmacist

Orthoptist

Orthoptist

Genetic Counsellor

Physiotherapist

Clinical Psychologist

Movement Neuroscientist

Speech Pathologist

Physiotherapist

Physiotherapist

Physical Therapist, Research Assistant



FUNDING

The Graduate School of Health at the University of Technology Sydney is funding this project.

WHY HAVE I BEEN ASKED?

We invite people across Australia to share their opinions on how we can improve stroke care.

We would like to hear from:

- People who have had a stroke – recently or in the past
- Family and other carers of people who have had a stroke
- Health professionals
- People from stroke organisations and support groups

IF I SAY YES, WHAT WILL IT INVOLVE?

We will ask you to share your opinions and ideas with us in **two (2)** interviews.

Interview 1

You can tell us what type of problems you have had with stroke care. We will ask you about initial opinions and ideas to fix these problems in stroke care.

We will ask a lot of people about their ideas. After these interviews, our team will work through all ideas to create a plan for future research studies.

Interview 2 – about 1 month later (optional)

If you agree, we will present to you the plan for future research studies based on everyone's ideas from the first interview. We will show you a few slides and explain the studies we have planned. We will ask your opinion on these future studies – whether they are good or not good ideas.

If you think that any of these future studies are a good idea, in future we will also ask whether you wish to be involved as a Consumer-Researcher - so that you can keep giving us feedback on the research. It is important to us that the research focuses on the needs of people affected by stroke.

It is entirely up to you whether you want to be part of this study's interviews or surveys. It is also entirely up to you whether you want to be part of any proposed future research studies as a Consumer-Researcher. You can say YES or NO to any part of the research, at any time. You can change your mind at any time without giving a reason.



IF I AM INTERESTED, HOW CAN I SHARE MY OPINION AND IDEAS?

You can choose HOW you share your opinions and ideas with us:

Option 1 - Individual Interview

You can share your ideas and opinions with a researcher

- a carer (family, formal carer, interpreter) can assist you if needed
- we can chat by:
 - Telephone
 - Internet / Online (Zoom)
 - Face-to-Face (only if safe and COVID-19 restrictions are lifted)
- interviews will take about 1 hour; it's up to you when and how long we speak
- we can take breaks to eat, drink, rest, stretch, and toilet.

OR

Option 2 - Group Interview

You can join a small group to discuss your ideas and opinions with others

- your group may include other people affected by stroke, carers, health professionals, or people from stroke support groups.
- your group may have up to 6 people. You may know some people already.
- our team will guide the group discussion

- a carer (family, formal carer, interpreter) can assist you if needed
- group interviews will be held:
 - Internet / Online (Zoom)
 - In person (only if safe and COVID-19 restrictions are lifted)
- group interviews will take about 2 hours to give everyone a chance to speak
- each person will have time to share their opinions
- we will take breaks to eat, drink, rest, stretch, and toilet.

Before we seek your feedback we will also ask for some background information about your history of stroke, health status, and care needs using a questionnaire that will take about 15-30 minutes. We will not collect personal information that will identify you.

WHERE AND WHEN ARE THE INTERVIEWS?

Dates, times and location of group interviews will be advised when you contact us. Interviews will be held during September, October, November 2021.

For internet / online (Zoom) interviews, you will need access to the internet via a computer, laptop, iPad, or mobile phone.



WHAT IF I HAVE COMMUNICATION CHALLENGES?

Stroke survivors may have a carer, interpreter, or support person assist them.

If you have health or communication challenges, we will:

- take time to hear your ideas
- use large text and images on a screen to prompt you
- speak clearly with good volume

WHAT IF I CANNOT JOIN AN INTERVIEW?

Option 3 – Written Comments

You can share your opinions and ideas by sending WRITTEN comments via:

- online form – click here <https://redcap.link/ICTUS>
- paper form – a form can be mailed to your address

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

Email us: poststrokestudy@uts.edu.au

Phone us: 0407 584 635 [Research Assistant Mr Esminio Rivera]

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 RISKS/INCONVENIENCE?

We hope that these discussions will be a positive experience for you. But we understand that sharing your opinions and ideas, especially with other people in a group, may be uncomfortable, emotional and tiring. If this occurs, you may take a break or leave the discussion – you will not have to continue if you can't. Our team can offer support and provide information about counselling services to assist you.

You may feel embarrassed about sharing your thoughts with a group of people – some may be strangers, some you may know. You may be worried about sharing negative opinions about stroke care and upsetting other people in the group. **We want to hear many opinions and ideas, no matter how different – there are no right or wrong opinions or ideas.** We will guide the discussion so each person can freely share opinions, with privacy, sensitivity and respect. Our team will support you in safely and freely sharing your ideas.

You may worry about how your opinions or ideas are reported. The interviews will be voice-recorded to clearly record each person's opinion – our team will review



the recordings and make detailed notes. You can ask to review the discussion notes and ask for corrections. We will not share your recordings with anyone. There is also some inconvenience in the time it takes to participate in a research study. To cover the time and effort involved, you will receive a \$50 gift card. We will also provide light refreshments for in-person interviews.

DO I HAVE TO TAKE PART IN THIS STUDY?

No, it is up to you whether you take part or not. Participation is truly voluntary.

We will ask if you consent to take part in this study. You can indicate YES or NO by telling us in words, pointing on the consent form, nodding your head, clicking the online form, or signing the consent form.

WHAT WILL HAPPEN IF I SAY NO?

If you decide not to take part, it will not affect your relationship with our team or University of Technology Sydney.

You can stop your involvement at any time by contacting us on 0407 584 635 [Research Assistant Mr Esminio Rivera] or poststrokestudy@uts.edu.au. Any discussion notes relating to you will be removed from the study files.

CONFIDENTIALITY

With your consent, the research team will collect and use information from you for this research. All of your information will be treated confidentially. No personal information will be passed on to anyone outside our team. We will not collect or record any personally-identifying information from you.

Your shared information and interview voice recordings will only be used for this study with your permission, except as required by law. Your voice-recordings from interviews will be stored on a password-protected, secure, computer at the University of Technology Sydney. Only our team will have access to these recordings to help us make notes. Recordings will be destroyed at end of the study.

We may report the study findings at research conferences and health service meetings (hospitals, health care facilities). In any presentation or publication, you will not be identified.

If we quote anything you said during interviews, we will not name you – we will use a general label:

“Participant SP1 – a person affected by stroke”

“Participant SC1 – a carer of a person affected by stroke”

You will be offered a copy of the final study report.



WHAT IF I HAVE QUESTIONS OR CONCERNS?

You can contact our team by:

- phoning our Research Assistant (Mr Esminio Rivera) 0407 584 635
- emailing our team poststrokestudy@uts.edu.au
- emailing our team leader (Ms Beata Bajorek) Beata.Bajorek@uts.edu.au

You can write your questions here so that you do not forget to ask us:

WHAT IF I HAVE OTHER CONCERNS OR A COMPLAINT?

This study has been approved by the University of Technology Sydney Human Research Ethics Committee [UTS HREC]. The study number is **ETH21-6371**.

To contact an independent person about this study, please:

- phone A/Professor Toby Newton-John 02 9514 7241
- email Toby.Newton-John@uts.edu.au

If you have any concerns or complaints about this research please:

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

Any concerns raised will be treated confidentially and investigated. You will be informed of the outcome.

You will be given a copy of this form to keep