



ICTUS Research Study

Improving Care, research Translation, and treatment Usage in Stroke

Information for Health Professionals involved in Stroke Care and Stroke Organisation Representatives

WHAT IS THIS RESEARCH ABOUT?

This aim of this study is to identify practical ideas and strategies for addressing gaps in local stroke care in the Australian setting. Specifically, we are seeking to canvas the perspectives of people affected by stroke as well as those who are directly **involved in providing stroke care and support, such as health professionals and representatives from stroke organisations and stroke support groups.**

We are interested in hearing a range of:

- opinions about gaps in current stroke care across the care continuum, based on your specific and unique experiences and observations
- ideas on the ways we might close these gaps in stroke care
- thoughts on how allied health professionals (*Psychologists, Pharmacists, Physiotherapists, Orthoptists, Speech Pathologists, Genetic Counsellors*) in particular, can help improve and better support stroke care whether in terms of acute and/or chronic care, or hospital or community-based care.

Your opinions will help us to designed targeted research studies where we can test any ideas and help improve stroke care. By bringing together the perspectives of patients, carers, health professionals and stroke care advocates, we can identify stroke care priorities as well as key strategies suggested to address these. This will facilitate the co-design of research studies that can be taken forward, where we will invite you to be part of the research team as a co-researcher.

WHO IS DOING THE RESEARCH?

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

| | |
|--------------------------|--|
| Beata Bajorek | Clinical Pharmacist |
| Michelle Courtney-Harris | Orthoptist |
| Amanda French | Orthoptist |
| Chris Jacobs | Genetic Counsellor |
| David Kennedy | Physiotherapist |
| Ian Kneebone | Clinical Psychologist |
| Alana McCambridge | Movement Neuroscientist |
| Emma Power | Speech Pathologist |
| Camilla Quel De Oliveira | Physiotherapist |
| Peter Stubbs | Physiotherapist |
| Esminio Rivera | Physical Therapist, Research Assistant |

FUNDING

The Graduate School of Health at the University of Technology Sydney is funding this project through a research seed grant.



WHY HAVE I BEEN ASKED?

We are inviting 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

We will ask you about problems or challenges you have experienced and/or observed with stroke care. We will ask for your initial opinions and ideas on how to address these in Interview 1. After completing first interviews with a range of people, our research team will work through all ideas to create a plan for future research studies.

Interview 2 – approximately 1 month later (optional)

If you agree, we will present to you the draft plan for future research studies based on everyone's ideas from the first interview. We will explain the studies and ask for your opinion on these future studies.

If you think that any of these future studies are a good idea, we will also ask whether you wish to be involved as a Consumer-Researcher or member of our research team - so that you can keep giving us feedback on the research and assist in the study co-design process. It is important to us that the research focuses on the needs of people affected by stroke and those providing stroke care and support. It is entirely up to you whether you want to be part of this study. It is up to you whether you decide to be part of any proposed future research studies. 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.

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

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 in an individual interview

- 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 is up to you when and how long we speak

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
- 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.



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.

To cover the time and effort involved, you will receive a \$50 gift card per interview. We will also provide light refreshments for in-person interviews.

WHAT IF I CANNOT JOIN AN INTERVIEW?

Option 3 – Written comments

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

- online form – click here <https://redcap.link/ICTUS>

Your comments will remain confidential – they will be stored securely by our team. All personally-identifying information will be removed from your form or email so that you cannot be identified. You can also indicate to us if you would prefer that your professional details (e.g., occupation, position, stroke organisation) are also not disclosed. We will ask you how you would prefer to be identified in any study reports.

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. 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.

We want to hear many opinions and ideas, no matter how different – there are no right or wrong opinions or ideas.

We will guide group interviews so each person can freely share opinions, with privacy, sensitivity and respect. Our team will support you in safely and freely sharing your ideas.

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.

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 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 any 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”

“Participant HP2 – a Health Professional”

“Participant SO5 – a representative of the National Stroke Foundation”

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