

PARTICIPANT INFORMATION SHEET

UTS HREC REF NO. ETH22-7082- Understanding the impact of Stroke on family (STARS study)

WHO IS CONDUCTING THIS RESEARCH?

Our names are:

- Dr Brooke Ryan (Univeristy of Technology Sydney)
- Dr Rachelle Pitt (Queensland Health)
- Associate Professor Emma Power (Univeristy of Technology Sydney)
- Associate Professor Dana Wong (Latrobe Univeristy)
- Dr Karli Treyvaud (Latrobe Univeristy)
- Dr Kirstine Shrubsole
- Professor Vanessa Cobham (University of Queensland)
- Professor Ian Kneebone (Univeristy of Technology Sydney)

We are academics interested in stroke, child youth and mental health and families.

WHAT IS THE RESEARCH ABOUT?

The purpose of this research is to better understand how we can help families who have had a stroke. Families can face significant and stressful challenges when a parent experiences a stroke. To start addressing this need, we want to talk to families about their experiences as well as health professionals. The research will aim to be accessible to as many people as possible, recognising the importance of including people with communication and cognitive problems after stroke. There is an accessible version of this research information please ask us if you want a copy. The team will also work alongside stroke clinicians and parenting services to understand their needs in delivering optimal care. Together we want to ultimately design a family-based intervention, with child resources.

WHY HAVE I BEEN INVITED?

You have been invited to participate because you are a one of the following:

- Parent with stroke who have children living at home under aged 18
- Coparent of parent with stroke
- Child of a parent with stroke aged under 18
- Stroke health professional who has had a parent with stroke on their caseload in the last 12 months
- Parenting practitioner.

If you are family living with stroke, everyone in your family can be involved if they want to. It will be their own choice. Members of you family can still participate even if someone else in the family does not. If your children are old enough, we can also include them in the study. We have a different consent form for children in our study.

FUNDING

Funding for this project has been received from the Stroke Foundation. Dr Brooke Ryan was awarded the funding in for the research to be conducted from 2022-2023.

WHAT DOES MY PARTICIPATION INVOLVE?

Your participation in the study will involve:

- answering a short demographic questionnaire that will take approximately 10 minutes to complete
- participate in a 60- 90-minute interview / focus group that will ask questions about the impact of stroke on families, what resources are needed to support families, and how service providers can better help.
- interviews/focus groups being video recorded and transcribed so that we can conduct an analysis what you have said for study publications.
- participating in person or online depending on your preference, your location in Australia, and Covid-19 restrictions.

ARE THERE ANY RISKS/INCONVENIENCE?

This study is unlikely to cause harm. However, there may be some discomfort to you:

- You will be asked sensitive questions about the impact of stroke on families.
- Our questions may cause you some distress.

DO I HAVE TO TAKE PART IN THIS RESEARCH PROJECT?

Participation in this study is voluntary. It is completely up to you whether you decide to take part. If you decide not to participate, or to withdraw from the study, it will not affect your relationship with the researchers or the University of Technology Sydney.

WHAT IF I WITHDRAW FROM THIS RESEARCH PROJECT?

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason, by contacting Dr Brooke Ryan (brooke.ryan@uts.edu.au). If you decide to leave the research project, we will not collect additional personal information from you (e.g., name, address, date of birth etc.), although information already collected will be retained. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want us to do this, you must tell us before you join the research project.

WHAT WILL HAPPEN TO INFORMATION ABOUT ME?

By signing the consent form, you consent to the research team collecting and using personal information about you for the research project. All this information will be treated confidentially. We will assign you a participant code and deidentify all written transcripts. It will not be possible to de-identify the video data collected. However, this data will be stored on secure password protect network. Your information will

only be used for the purpose of this research project, and it will only be disclosed with your permission, except as required by law.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your permission. We will use a made-up name for you in any publications and present your personal data in a way that it can't be linked back to you.

In accordance with relevant Australian and/or NSW Privacy laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

The results of this research may also be shared through open access (public) scientific databases, including internet databases. This will enable other researchers to use the data to investigate other important research questions. Results shared in this way will always be de-identified by removing all personal information (e.g. name, address, date of birth etc.).

WHAT IF I HAVE ANY QUERIES OR CONCERNS?

If you have queries or concerns about the research that you think we can help you with, please feel free to contact Brooke Ryan on [brooke.ryan@uts.edu.au].

You will be given a copy of this form to keep.

NOTE:

This study has been approved in line with the University of Technology Sydney Human Research Ethics Committee [UTS HREC] guidelines. If you have any concerns or complaints about any aspect of the conduct of this research that you wish to raise independently of the research team, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au] and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

CONSENT FORM

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(STARS study)**

I _____ *[participant's name]* agree to participate in the research project being conducted by Dr Brooke Ryan Brooke.ryan@uts.edu.au I understand that funding for this research has been provided by Stroke Foundation.

I have read the Participant Information Sheet, or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research as described in the Participant Information Sheet.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time without affecting my relationship with the researchers or the University of Technology Sydney.

I understand that I will be given a signed copy of this document to keep.

I am aware that I can contact Dr Brooke Ryan Brooke.ryan@uts.edu.au if I have any concerns about the research.

Name and Signature [participant]

___/___/___
Date

Name and Signature [researcher or delegate]

___/___/___
Date