

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 HAS MY CHILD BEEN INVITED?

Your child has been invited to participate because we would like to talk to them about their experiences with stroke, find out how much they know about stroke and ask them about how best we can help other children after stroke. If you have a young child, we will ask them to draw, and engage with us through games and activities rather than just talking.

FUNDING

Funding for this project has been received from Stroke Foundation.

WHAT DOES MY CHILD'S PARTICIPATION INVOLVE?

If you decide to allow your child to participate, they will be invited to an individual interview by themselves or with their siblings.

The interviews will be video recorded and transcribed so that we can conduct an analysis for study publications.

Your child will participate 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 your child:

- Your child may be asked sensitive questions about the impact of stroke on families.
- Our questions may cause some distress.

Our team have experience working with children and will do as much as we can to not cause distress. We may recommend your child speak with their GP (doctor) who is already familiar with their history and who will be best placed to offer initial assessment and support continuity of care. Other services that can be recommended include:

- Kids Helpline | Phone Counselling Service 1800 55 1800 or <https://kidshelpline.com.au>
- Headspace <https://www.headspace.com/>

DOES MY CHILD HAVE TO TAKE PART IN THIS RESEARCH PROJECT?

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

WHAT IF I WITHDRAW MY CHILD FROM THIS RESEARCH PROJECT?

If you wish to withdraw your child 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 your child (e.g., name, address, date of birth etc.), although personal information already collected will be retained. You should be aware that data collected up to the time you withdraw your child will form part of the research project results. If you do not want us to do this, you must tell us before you give consent for your child to join the research project.

WHAT WILL HAPPEN TO INFORMATION ABOUT MY CHILD?

By signing the consent form, you consent to the research team collecting and using personal information about your child for the research project. All this information will be treated confidentially. Your child's 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 your child cannot be identified, except with your permission.

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 concerns about the research that you think we can help you with, please feel free to contact Dr Brooke Ryan 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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I _____ *[name of Parent/Guardian]* give permission for my child _____ *[name of child]* 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 [if applicable].

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 allow my child to participate in this research project as described and understand that I am free to withdraw my child 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 of child [please print]

Signature or mark of child (if able)

____/____/____
Date

Name Parent/Guardian [please print]

Signature of Parent/Guardian

____/____/____
Date

Declaration by researcher*

I have given a verbal developmentally appropriate explanation of the research project; its procedures and risks and I believe that the child has understood that explanation and is willing to participate.

Signature _____

____/____/____
Date

Name [please print] _____