

UTS HREC REF NO. ETH22-7082

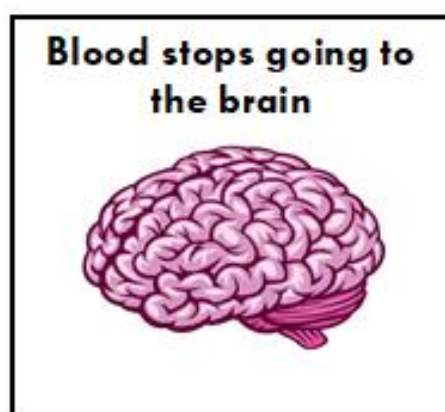
## Information Sheet for Parents with Stroke

Understanding the impact of Stroke on family  
**(STARS study)**



You are invited to take part in **stroke** research.

A stroke happens when **blood flow** to the **brain** is **stopped**.



## **What is this project about?**

We would like to talk to you about the **impact stroke has on a family.**

**The impact stroke has on a family.**



We want to find out ways we can **help families.**

We want to make resources for **children.**

**We want to help families after stroke.**



## **Who can participate?**

- **You and your family can participate.**
- Everyone in your family can be involved or not. It will be their **own choice.**
- You can participate in your family do not want to.
- Your family can participate if you do not want to.
- **If your children are old enough** and agree to talk to us, we can include them in the study.

**Children can participate if they want.**



## **How do I participate?**

- You will be invited to a **group discussion** (focus group).
- The group discussion will last 60-90 minutes.
- The group discussion will be with **other parents with stroke**.



- You can have **someone to support you** if you need to.
- Some people in the group may need help with communication or physical access.
- If you live in **Sydney**, you can come to UTS.

- If you live **outside of Sydney**, you can do the interview via the internet.
- If the **COVID-19 restrictions** mean, we cannot meet face to face we will interview via the **internet**.

**We may use online technology if needed**



- We will **video record** the interview.

**We will video record**



## How does my family participate?

- Your family will be invited to a different discussion.
- Your child will be invited to an individual interview with the researchers.
- If you have **more than one child**, they can **participate together or separately**.

**Your child will participate in a different interview.**



## **What information will I need to give?**

- We will collect information about your family. For example, you and your family member's **name, age, gender**.
- We will collect information about **your stroke**.

**We will you for personal and stroke information**



## **What questions will we ask?**

- **We will ask you questions** about **how life has changed** for your family because of your stroke.
- We will ask you about **support that would help you** after stroke.
- We want to know **how best to help children** after stroke.

### **How will the information be kept?**

- We will keep any information at **The University of Technology Sydney** on a password-protected electronic computer.
- All information will be **confidential**.
- To **protect your privacy**, all information about you will be **labelled with a code number**.


### **How long will you keep my information for?**

- All your information from the study will be stored securely for 5 years.

### **What will happen to the information I give?**

- The results may appear in journal publications and conference presentations.

**We will use the information for publications.**

A photograph of a woman in a blue dress standing at a podium, presenting to an audience in a conference room. The room has large windows and a whiteboard in the background.



- **Your identity** in publications **will be kept private.**
- We will send you a summary of the results of this study.

### **What happens if I decide I want to be involved?**

If you agree to participate, we will ask you to **Consent.**



If you consent, it means that **you agree:**

- **To participate** in an interview
- We can collect information about you and securely store it for 5 years.
- We can video or audio record you to help us remember what you say.

### **What if I decide I do not want to be involved?**

- You **do not have to participate**. It is **your choice**.
- You can start participating and then **change your mind**.
- You can ask questions at any time.
- You can stop at any time.



### **What happens if I start the study and then change my mind?**

**You can stop** participating in this research **at any time**. You can stop even during the group discussion.

To stop doing the research **contact Brooke Ryan:**



Email: [brooke.ryan@uts.edu.au](mailto:brooke.ryan@uts.edu.au)

### **Who has approved this research?**

This study has been cleared by the human **ethics committees** of the **University of Technology Sydney** in accordance with the guidelines from the National Health and Medical research Council.

### **How will I find out about the results of the study?**

A summary of the results can be posted or emailed to you.

## **What if I have a complaint?**

If you would like to speak to an officer of the University not involved in the study, you may contact:

**The Ethics Officer** at the **University of Technology Sydney**



on phone: +61 2 9514 2478

## **What if I have more questions?**

- If you would like some more information, please contact

**Dr Brooke Ryan:**

Email: [brooke.ryan@uts.edu.au](mailto:brooke.ryan@uts.edu.au)



## Consent Form for Participants with Stroke

### Understanding the impact of Stroke on family (STARS study)



I \_\_\_\_\_ (please write full name)

agree to participate in this research.

#### I understand:

- what this study is about
- that **I do not have to participate** if I do not want to
- that I can **stop at anytime**
- that I can ask questions at anytime

**I understand that this study:**

- will **help researchers** learn more about stroke and families
- may **not directly benefit me**
- **will not affect my relationship** with the University of Technology Sydney or any health service I am receiving treatment in.

**I understand the information I give:**

- Will be **video recorded**
- Will be **stored safely** at **University of Technology Sydney**
- Will be kept securely.

**To ask more questions contact:**

**Dr Brooke Ryan**



Email: [brooke.ryan@uts.edu.au](mailto:brooke.ryan@uts.edu.au)

Participant Signature: \_\_\_\_\_ Date \_\_/\_\_/\_\_