



PARTICIPANT INFORMATION SHEET

What are the top research priorities for stroke in Australia?

SURVEY

The Stroke Foundation and Centre for Research Excellence to Accelerate Innovation and Translation in Stroke Trials are working together to determine the **top research priorities for stroke** in Australia.

What is the project about?

We want to find out **which research topics matter most** to people who have experienced stroke, their families, carers and health professionals.

To do this, we'll use a **survey** and a **workshop** to decide which research areas are most important.

We will use these research priorities to guide Stroke Foundation and other researchers in their work.

Who is involved in this project?

A **team of people** is working on this project. They are all listed at the end of this document.

Am I eligible to complete this survey

You can complete this survey if you are over 18 years old, live in Australia and are either a:

- **survivor** of stroke
- **family member, carer or support crew** for someone who has had a stroke.
- **health professional** working in the area of stroke

What am I being asked to do?

We would like you to complete this online survey. In the survey, you'll rank each research priority based on how important you think it is.

At the end of the survey, you can decide if you'd like to be invited to participate in a workshop. If you are invited to participate in a workshop, we will send you a further information statement.

We may need to run the survey a second time with a smaller group of people. If we do this, you may be sent another invitation to participate in the next month or two.

How much time will it take?

The survey will take 15-20 minutes.

Can I get help?

Our team are available for any questions and to help with completing the survey, including if you would like to receive a paper copy. Please contact **Michelle Adamson**:

Phone: 03 9918 7215

Email: madamson@strokefoundation.org.au

Are there any risks?

We don't expect that completing the survey will have any risks for you. However, if it does raise issues for you, please contact either:

StrokeLine - Stroke Foundation service for free and confidential advice provided by health professionals

Phone: 1800 787 653

Email: strokeline@strokefoundation.org.au

Beyond Blue mental health support service (available 24 hours a day)

Phone: 1300 22 4636.

What are the potential benefits?

By identifying research priorities, we can focus on areas that will have the most benefit to people who have experienced stroke.

Is participation voluntary?

Yes, participation is entirely voluntary. If you choose not to participate, that's okay.

Can I withdraw from this project?

Certainly! You can withdraw at any time.

What will happen to my information?

- **Confidentiality and privacy:**
 - Your survey answers will remain **anonymous**.
 - We won't be able to identify you from your responses.
- **Data storage:**
 - All information will be stored **securely** on University of Newcastle and Hunter Medical Research Institute servers.
- **Publishing:**
 - We will report the results in journal articles and conference presentations.
 - We will also tell people about what we found through Stroke Foundation social media channels, newsletters and other media.
 - Individual participants will not be identified in any publications.

Complaints or any concerns

If you have any concerns or complaints, please contact the Principal Investigator. You can also speak with an independent person regarding concerns or complaints by contacting the Human Research Ethics Committee's Secretariat on:

Phone: +61 (02) 4921 6333

Email: human-ethics@newcastle.edu.au.

Post: University Drive, Callaghan NSW 2308, Australia

If I want to participate, what do I do?

- Read and make sure you understand this Information Statement

If there is anything you do not understand, or if you have questions, contact

Coralie English	Coralie.english@newcastle.edu.au
Michelle Adamson	madamson@strokefoundation.org.au

If you decide to participate, please complete the online survey.

Research Team

Investigator	Organisation
Prof. Coralie English	University of Newcastle, Stroke Trials CRE
Prof. Leonid Churilov	University of Melbourne, Stroke Trials CRE
Assoc Prof Elizabeth Lynch	Flinders University
Mr Adrian O'Malley	Lived Experience Expert (survivor of stroke), Stroke Trials CRE
Ms Brenda Booth	Lived Experience Expert (survivor of stroke), Stroke Trials CRE
Mr Kevin English	Lived Experience Expert (survivor of stroke), Stroke Foundation
Ms Kim Beesely	Lived Experience Expert (carer), Stroke Trials CRE
Dr Karly Zacharia	University of Newcastle
Dr Tope Adeyoyibi	Stroke Foundation
Mr Kelvin Hill	Stroke Foundation
Ms Michelle Adamson	Stroke Foundation
Dr Chris Lassig	Stroke Foundation