



Preventing Stroke Research Priorities Project (RPP)

The first STOPstroke Survey

Participant Information Sheet

Research team

| Role & Name | Institution | Contact |
|---------------------------------|-----------------------------------|------------------------------------|
| Chief Investigator | | |
| A/Prof Seana Gall | University of Tasmania | seana.gall@utas.edu.au |
| STOPstroke Investigators | | |
| Prof Amanda Thrift | Monash University | Amanda.Thrift@monash.edu |
| A/Prof Judith Katzenellenbogen | University of Western Australia | judith.katzenellenbogen@uwa.edu.au |
| Prof Mark Nelson | University of Tasmania | mark.nelson@utas.edu.au |
| Prof Timothy Kleinig | Royal Adelaide Hospital | Timothy.Kleinig@sa.gov.au |
| Prof Valery Feigin | Auckland University of Technology | valery.feigin@aut.ac.nz |
| Prof Dominique Cadilhac | Monash University | Dominique.Cadilhac@monash.edu |
| Dr Lee Nedkoff | University of Western Australia | lee.nedkoff@uwa.edu.au |
| Dr Joosup Kim | Monash University | joosup.kim@monash.edu |
| A/Prof Monique Kilkeny | Monash University | monique.kilkenny@monash.edu |

Invitation

You are invited to participate in the STOPstroke survey which forms part of the Preventing Stroke Research Priorities Project (RPP). This survey is the first step in collecting your questions about preventing stroke. It will be followed by a second survey to prioritise the questions. Our aim is to generate a list of the 'Top 10' unanswered research questions in stroke prevention.

Background information

Do you know that 1 in 4 people will have a stroke in their lifetime? This survey is an opportunity to tell us what you would like to know about **preventing stroke**.

Stroke is one of the biggest causes of death and disability in the world today. In Australia and New Zealand, stroke is the 3rd leading cause of death and the leading cause of adult disability. Stroke attacks the brain – our most vital organ. A stroke occurs when blood supply to the brain is cut off. Without blood, the brain can become damaged. Every stroke is different depending on where in the brain it strikes and how severe it is. What is common is the life-long impact it can cause to the people affected by stroke and those who care for them.

What we do know is that around 80% of strokes are preventable. That means for the 27,000 people who experienced stroke in Australia during 2020, around 21,000 could have been prevented because they were caused by risk factors that we can control with lifestyle and medication such as high blood pressure, smoking, poor diet, alcohol use, and physical inactivity. Stopping stroke will have major benefits for the health and lifestyle of those at risk of stroke and significant savings within the health system and economy more broadly.

In 2020, the National Health and Medical Council of Australia (NHMRC) funded a 5-year research program focused at preventing stroke. The grant is called *Synergies TO Prevent stroke or STOPstroke*. This survey is one of the key ways the STOPstroke researchers are engaging with the community. The STOPstroke researchers would like to hear what questions you have about how to stop strokes from happening.

Why we need your help

The STOPstroke researchers are looking to understand the priorities of the Australian and New Zealand community and clinicians for the prevention of stroke. Your questions will help us to ensure our research addresses the questions that matter about preventing stroke.

Your questions might be about what you can do to reduce your chance of having a stroke, or you may have questions about what things the government might do to help less people have strokes.

Who should take part in the survey?

We want ideas and thoughts from people with different experiences and backgrounds. We would like to hear from anyone over the age of 18, living in Australia or New Zealand who is interested in preventing stroke. You might for example be someone who has a family member, friend or work colleague affected by stroke. We are also interested to hear from people with lived experience of stroke; caregivers; and health professionals (including nurses, physicians, pharmacists, and others) who care for people at risk of stroke or who now live with stroke. People who do not know much about stroke are also encouraged to participate.

Please ask others to complete the survey. We want to ensure our researchers are aware of the questions that matter to lots of people.

What is involved if you take part in the survey?

The survey will take about 10 minutes to complete. It is in two parts. The first is where you get to provide your questions on preventing stroke. The second will help us to check if we have a wide range of people taking part in the survey. In part 2 of the survey, you can select 'prefer not to say' if you would rather not answer any of all of the questions in that part.

At the end of the survey you will be asked:

1. If you would like to be kept informed on progress with the project via email;
2. if you would like to take part in a second phase of this project to help decide which of the questions currently unanswered by research are the most important; or
3. If you would be interested in participating in a workshop as the final part of the priority-setting project.

If you agree, you will be asked to provide your name and contact information. We store this information separately to the survey responses, so the survey itself is anonymous.

We do not anticipate any risks involved in participating in the survey. Participation in this survey is voluntary.

Will your answers be kept confidential?

All personal information will be kept confidential when we release the results of this survey, we will never name any individual who took part in this survey. The survey data will be securely stored at the Menzies Institute for Medical Research at the University of Tasmania and destroyed five years from the publication of results.

Who is conducting this survey?

STOPstroke is coordinated by the Menzies Institute for Medical Research at the University of Tasmania and involves researchers located at Monash University, The University of Western Australia, Auckland University of Technology and the Royal Adelaide Hospital. A Steering Group of clinicians and community representatives is overseeing this project.

What will happen to the results?

Your question(s) will be gathered and examined together with questions we receive from everyone else who takes part in this survey. We will combine similar questions into summary questions and check to see if these have been answered by research. Questions that have not already been answered by research will be sent out in a second survey and be discussed at a workshop so that they may be prioritised. Based on the responses to the workshop, our Steering Group will make a top 10 list. The list will be published and used to influence future research decisions.

The Steering Group will also review the questions do not make the Top10 list because they have already been answered by research. There may be benefit in providing this data to another project to investigate gaps in knowledge about stroke. If the data is to be used any other project this would be the subject of a future human research ethics application.

Who can you contact for more information?

If you would like more information about the project, please contact:

Christine Farmer – STOPstroke Program Coordinator
Menzies Institute for Medical Research
University of Tasmania
email: christine.farmer@utas.edu.au
tel: +61 3 62267718

This study has been approved by the University of Tasmania Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, you can contact the Executive Officer of the HREC by email: human.ethics@utas.edu.au or telephone +61 3 6226 6254. The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote H0024539.

How can you agree to be involved?

By answering the questions in the survey, you are consenting to participate in this project.

*This Participant Information Sheet is yours to keep.
Thank you for your time and interest in this project.*