

Preventing Stroke Research Priorities Project

The second STOPstroke Survey

Participant Information Sheet



Research Team

Role & Name	Institution ¹	Contact
Chief Investigator		
A/Prof Seana Gall	UTAS	seana.gall@utas.edu.au
STOPstroke Investigators		
Prof Amanda Thrift	Monash	Amanda.Thrift@monash.edu
A/Prof Judith Katzenellenbogen	UWA	judith.katzenellenbogen@uwa.edu.au
Prof Mark Nelson	UTAS	mark.nelson@utas.edu.au
Prof Timothy Kleinig	RAH	<u>Timothy.Kleinig@sa.gov.au</u>
Prof Valery Feigin	AUT	valery.feigin@aut.ac.nz
Prof Dominique Cadilhac	Monash	Dominique.Cadilhac@monash.edu
Dr Lee Nedkoff	UWA	lee.nedkoff@uwa.edu.au
Dr Joosup Kim	Monash	joosup.kim@monash.edu
A/Prof Monique Kilkenny	Monash	monique.kilkenny@monash.edu

Invitation

You are invited to participate in the second STOPstroke survey which forms part of the Preventing Stroke Research Priorities Project.

We recently conducted the first STOPstroke survey that asked people in Australia and New Zealand to submit their questions about preventing stroke. We want to use this information to guide future research in the prevention of stroke.

Approximately 375 people submitted over 750 questions about preventing stroke. Our research team reviewed each submission, summarised similar questions, and identified the summarised questions already by answered by previous research. At the end of this process, we identified 47 summarised questions that might benefit from further scientific research.

Now we need to know how important you think the unanswered questions about preventing stroke are.

¹ University of Tasmania (UTAS); Monash University (Monash); University of Western Australia (UWA); Royal Adelaide Hospital (RAH); and Auckland University of Technology (AUT)

Who should take part in the survey?

This survey is open to anyone over the age of 18, living in Australia or New Zealand, who may be 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.

You do not need to have completed the first survey to do the second survey. We are looking to receive at least 300 responses. Please ask others to complete the survey. We want to ensure our researchers are aware of the questions about preventing stroke that matter to lots of people.

What is involved if you take part in the survey?

We invite you to rate each question on a scale of importance. There is a list of 47 questions. Please rate each question on a scale of importance to you. There are no right or wrong answers, this is about what questions you think researchers should focus on.

For example, if you think a question is very important and should be a top priority that researchers should focus on - then you can rate the question as **extremely important**.

Alternatively, you might think a question is valid, but you do not see it as a priority that researchers should focus on – then you can rate the question lower, as **not at all important**.

Sometimes you might read a question you are not sure about, in this case you can select the answer don't know.

We do not anticipate any risks involved in participating in the survey. Your responses are anonymous and participation in this survey is voluntary. We expect it will take you 15-20 minutes to complete. You may get a little tired reading through 47 questions, so you may wish to take a break as you make your selections. We have presented the questions in three sections to help break-up the reading time.

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; or
- 2. 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.

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 or organisation 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?

This project is led by a research team funded by a National Health and Medical Research Council (NHMRC) Synergy Grant. The grant, Synergies TO Prevent Stroke, also known as STOPstroke is coordinated by the Menzies Institute for Medical Research at the University of Tasmania and involves researchers located in Tasmania, Victoria, South Australia, Western Australia and New Zealand.

What will happen to the results?

After the survey has closed, we will use your answers to work out which are the most popular questions. We will then hold a workshop with community representatives, clinicians and researchers. At the workshop, the most popular questions will be discussed in more detail, and the top ten questions that need researching in stroke prevention will be agreed upon. The list will be published and used to guide future research decisions.

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 (HREC). 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.