

PARTICIPANT INFORMATION SHEET

ETH20-5088 EXPLORING TELEHEALTH CARE SEEKING BEHAVIOUR ACROSS THE STROKE CONTINUUM

WHO IS DOING THE RESEARCH?

My name is Muneeba Chaudhry and I am a student at University of Technology Sydney (UTS).
My supervisors are Dr Alana McCambridge and A/Prof Caleb Ferguson.

WHAT IS THIS RESEARCH ABOUT?

StrokeLine is a telehealth service provided by the Stroke Foundation.

This research will help us understand the reasons that people who have survived a stroke seek support from StrokeLine and the experience of using telehealth services such as StrokeLine in Australia.

Currently, there is limited knowledge about what stroke survivors think and experience when engaging in a telehealth-based service in Australia. This research will provide a better understanding of the role telehealth plays in the care of stroke survivors across the stroke continuum. The findings from this research will be useful for StrokeLine to understand how their services are meeting callers' needs and may identify gaps in the continuity of care of stroke survivors in Australia.

WHY HAVE I BEEN ASKED?

You have been invited to participate in this study because you expressed an interest in the study and have had a stroke.

You can be included in this study if you are 18 years or older, have contacted StrokeLine in the past 3 months, can communicate in English, have the capability for video-conferencing, and are able to give verbal consent.

IF I SAY YES, WHAT WILL IT INVOLVE?

If you decide to participate, I will invite you to:

- Undergo a short phone call with a member of the research team to explain the study process, determine if you are eligible to participate, and to answer any questions that you may have. We expect this to take no longer than 15 minutes.

If you are eligible to participate in the study, we will arrange a suitable time to perform the interview using the video-conferencing platform Zoom. You will have the option of keeping your video off and the call will be audio recorded only. The semi-structured interview should take no longer than 30-40 minutes of your time.

During the interview, you will be asked:

- To provide verbal informed consent that confirms you agree to participate in the study.
- To answer questions about your experience of seeking care through the StrokeLine service. You will be asked to provide as much information as possible and may be asked to provide specific details around your experiences.
- If required, you can take breaks during the interview and can have a support person with you.
- At the end of the interview, you will be provided an opportunity to debrief and ask any questions.

After the interview, you will be given the option of having the ~~will be sent an~~ electronic transcript of the interview sent to you by email to review. This will allow you:

- To look over what you have said
- To confirm if everything is correct
- To discuss any concerns with the researchers

ARE THERE ANY RISKS/INCONVENIENCE?

Yes, there are some minor risks or inconvenience.

Taking part in the study may be an inconvenience as it will take up to 1 hour of your time and this may cause you to experience fatigue or tiredness. There may also be some risk of emotional distress if you find the questions too difficult or confusing, if your experience with StrokeLine was negative or distressing, if your stroke journey has been difficult or has not been progressing as expected.

If you feel uncomfortable at any time during the interview, please notify the researcher, as they can reframe the question or allow you to take a break. You will always have the option of not answering a particular question if you do not wish to and you may choose to end the interview at any time.

DO I GET PAID FOR PARTICIPATION?

Yes. If you are eligible to participate in the study, you will be reimbursed for your time with an electronic gift card valued at \$30. This will be emailed to you after the interview process has been completed.

DO I HAVE TO SAY YES?

Participation in this study is voluntary. It is completely up to you whether or not you decide to take part.

WHAT WILL HAPPEN IF I SAY NO?

If you decide not to participate, it will not affect your relationship with the researchers, the University of Technology Sydney, StrokeLine, or the Stroke Foundation.

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason, by contacting Muneeba Chaudhry (see contact details below).

If you decide to leave the research project, we will not collect additional personal information from you. You should be aware that data collected up to the time you withdraw will form part of

the research project results unless otherwise stated by you. You may withdraw your interview data from the study without giving a reason. However, it may not be possible to withdraw your interview data if these have already been analysed and had your identifying details removed from the data.

CONFIDENTIALITY

By giving verbal consent you consent to the research team collecting and using personal information about you for the research project. All this information will be treated confidentially. The Stroke Foundation will not be made aware of who chooses to participate or not participate in this study.

All data will be de-identified using codes. The electronic data will be securely stored on the UTS network and will only be accessible by members of the research team. Any personal information will be stored separately to the data and will not be able to be traced back to individual participants. Your information will only be used for the purpose of this research project and will only be disclosed with your permission, except as required by law.

We plan to publish the results in a peer-reviewed journal. In any publication, information will be provided in such a way that you cannot be identified.

WHAT IF I HAVE CONCERNS OR A COMPLAINT?

If you have concerns about the research that you think I or my supervisor can help you with, please feel free to contact us.

Muneeba Chaudhry (student)

E: muneeba.t.chaudhry@student.uts.edu.au

P: 0421 998 023

Dr Alana McCambridge (supervisor)

E: alana.mccambridge@uts.edu.au

P: 02 9514 7222 (office phone)

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, 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.