

NSW Stroke Survivor Visual Rehabilitation Study

Participant information and consent – Stroke survivors and carers (Survey)

Participant information

WHO IS DOING THE RESEARCH?

This research is being conducted by a team of researchers from the University of Technology, Sydney.

WHAT IS THIS RESEARCH ABOUT?

The goal of the project is to determine what the care pathway is for stroke survivors with visual impairment in NSW. This will include information including the timing and tools used for vision screening, the type of management and referrals given, as well as the long term visual rehabilitation. From this information and the perspectives of both stroke survivors and stroke health care professionals, we aim to identify gaps in this pathway and potential barriers to appropriate care.

FUNDING

This project is being run independently by the participating researchers.

WHY HAVE I BEEN ASKED?

You have been invited to participate in this study because you are a stroke survivor or carer of a stroke survivor that was under the care of NSW healthcare professionals following the stroke event. You have expressed interest to one of your stroke or vision healthcare professionals about participating in this survey OR you have sought out this survey via an advertisement.

IF I SAY YES, WHAT WILL IT INVOLVE?

If you decide to participate, you will be asked to complete a survey about your experiences and perspectives on the vision care you received following the stroke event:

- The timing and nature of the stroke
- The impact of the stroke on your eyes and vision
- Your experience of vision assessment and treatment as an inpatient following the stroke
- The long term vision care plan provided to you and your perspective on how this affected your rehabilitation
- Your experience of any unmet care needs and what barriers you perceive to the delivery of adequate vision care.

The survey takes approximately 30 minutes to complete. If completing the survey online, you may save your responses at any point and resume the survey at a later time. Completing the survey does not obligate you to participate in any additional aspects of the study.

ARE THERE ANY INCONVENIENCE OR RISKS?

Yes, the time given (30 minutes) to complete the survey. You might also feel some uncomfortable emotions when discussing experiences of the stroke event and the recovery process. If so, you can stop the survey at any time without giving a reason.

DO I HAVE TO SAY YES?

You don't have to say yes. Participation in this study is voluntary. It is completely up to you whether or not you decide to take part. Your decision to participate, or not participate, will not affect your relationship with the researchers or UTS.

WHAT WILL HAPPEN IF I SAY NO?

Nothing, I will thank you for your time and won't contact you about this research again. If you decide not to participate in the survey, we will not collect additional personal information from you and destroy existing personal information and contact details, 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 Dr Amanda French - E: Amanda.French@uts.edu.au PH: (02) 9514 7238 or Shanelle Sorbello – E: Shanelle.Sorbello@student.uts.edu.au PH: (02) 9514 4106.

CONFIDENTIALITY

By signing the consent form 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 data will be securely stored on a UTS internal server, which is accessible only via an authenticated UTS system login and only available to researchers involved in the research. Participant names/contact details will be stored separately to digital recordings and transcripts. Any hardcopy transcripts will be stored in a locked drawer in a locked office. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

We plan to publish the results of the study in a scientific journal and present the results at relevant scientific conferences. 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 can help you with, please feel free to contact Dr Amanda French - E: Amanda.French@uts.edu.au PH: (02) 9514 7238 or Shanelle Sorbello – E: Shanelle.Sorbello@student.uts.edu.au PH: (02) 9514 4106.

NOTE:

This study has been approved by the University of Technology Sydney Human Research Ethics Committee. 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.

PARTICIPANT CONSENT PAGE

I _____ agree to participate in the research project NSW Stroke Survivor Visual Rehabilitation Study being conducted by University of Technology, Sydney. I understand that this study is being conducted independently by UTS researchers.

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research as described in the Participant Information Sheet.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time without affecting my relationship with the researchers or the University of Technology Sydney.

I understand that I will be given a signed copy of this document to keep.

I agree that the research data gathered from this project may be published in a form that does not identify me in any way

If I have any concerns about this research I am aware that I can contact
 Dr Amanda French - E: Amanda.French@uts.edu.au PH: (02) 9514 7238 or
 Shanelle Sorbello – E: Shanelle.Sorbello@student.uts.edu.au PH: (02) 9514 4106 of the
 University of Technology Sydney or the UTS Ethics Secretariat (02 9514 2478) and quote the
 approval number [*****].

 Name and Signature [participant] _____/_____/_____
 Date

 Name and Signature [researcher or delegate] _____/_____/_____
 Date

Please return this signed consent page to Shanelle Sorbello from the University of Technology Sydney [Shanelle.sorbello@student.uts.edu.au]

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