

Stroke Survivor's experiences: Access to information and services during recovery

You are invited to take part in this research project called **Stroke Survivor's experiences: Access to information and services during recovery**. You have been invited because you are a young stroke survivor (under the age of 65 years).

Investigators

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Description of the study

This project will investigate the information and services stroke survivors have access to and explore some of the gaps, challenges, and positive experiences during transition into the community setting.

The project is supported by the Caring Futures Institute, College of Nursing and Health Sciences, Flinders University.

Purpose of the study

This project invites you to answer a survey that aims to find out more about:

- Your recovery journey
- The types of information you were given after your stroke
- Some of the things that have been helpful and unhelpful for you in your recovery

Benefits of the study

Sharing your experiences will help the researchers to understand how stroke survivors can be better supported through recovery.

Participant involvement and potential risks

If you agree to participate in the research study, there are three parts to this survey:

- Questions to provide some information about you (Q1-Q5). This information will not be used to identify you. It will be used to describe the group of people who completed the survey.
- Questions about when you had your stroke and the services you had access to (Q6-Q11).
- Questions about the information you received during your recovery and the support you received to access services and support in the community setting (Q12-Q21)

The survey will take about 15 - 20 minutes to complete and participation is entirely voluntary.

The researchers do not expect the questions to cause any harm or discomfort to you. However, if you experience feelings of distress or frustration as a result of answering questions about your experiences, please let the research team know immediately. You can also contact the following services for support:

- Lifeline – 13 11 14, www.lifeline.org.au
- Beyond Blue – 1300 22 4636, www.beyondblue.org.au

Withdrawal Rights

You may, without any penalty, decline to take part in this research study.

If you decide to take part and later change your mind, you may, without any penalty, withdraw at any time without providing an explanation.

To withdraw, you may just refuse to answer any questions or close the internet browser and leave the online survey.

Any data collected up to the point of withdrawal will be securely destroyed. You have the right to withdraw at any point during the study up until the survey is submitted.

Once surveys have been submitted, they will be anonymous (we will not know who completed the questionnaire) so there will be no way of withdrawing your answers from the data once submitted.

Confidentiality and Privacy

Only researchers listed on this form have access to the individual information provided by you. The information you share will not be linked to you. The research outcomes may be presented at conferences, written up for publication or used for other research purposes as described in this information form. However, the privacy and confidentiality of individuals will be protected at all times. You will not be named, and your individual information will not be identifiable in any research products.

No data will be shared or used in future research projects without your specific consent.

Data Storage

The information collected may be stored securely on a password protected computer and/or Flinders University server throughout the study. All data will be securely transferred to and stored at Flinders University for at least five years after publication of the results. Following the required data storage period, all data will be securely destroyed according to university protocols.

How will I receive feedback?

On project completion, a short summary of the outcomes will be provided to all participants via email or mail. Please contact Belinda Lange on belinda.lange@flinders.edu.au or 722 18285 to request a copy of this report.

Ethics Committee Approval

The project has been approved by Flinders University's Human Research Ethics Committee (project number 5157).

Queries and Concerns

Queries or concerns regarding the research can be directed to the research team. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics & Compliance Office team via telephone 08 8201 2543 or email human.researchethics@flinders.edu.au.

Thank you for taking the time to read this information sheet and if you accept our invitation to be involved, please follow the link <https://tinyurl.com/StrokeInfoStudy> and complete the Consent Statement to access the survey.