



PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Title: Harnessing the power of co-design to develop digital solutions and improve health self-efficacy after stroke

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Description of the study

This project will investigate how to use a website to help survivors of stroke and carers to get information to manage their health and wellbeing. After designing the website, we will ask survivors and carers to test it, to make sure it is easy to use. We will refine the website if there are problems.

We will then test the website on different groups of survivors and carers to see who the solution looks likely to help. This will guide future research.

This project is supported by Flinders University, College of Nursing and Health Sciences.

Purpose of the study

This project aims to find out which groups of survivors of stroke and carers are likely to benefit from a website to enhance self-efficacy (their confidence in their ability to look after their health and wellbeing).

Benefits of the study

The sharing of your experiences will help to design the website so it meets the needs of people with stroke and carers. We anticipate that working closely with people with lived experience of stroke (people with stroke and carers) will assist us in developing a website that is user-friendly and helpful to other people with stroke and carers.

Participant involvement and potential risks

If you agree to participate in the research study, you will be asked to:

- Trial using the website, and provide feedback whether information is easy to find, and is relevant to your needs.
- This trial session will last approximately 1 hour, will occur over Microsoft Teams and will be videorecorded.
- Look through and try using the website for two weeks.
- Participate in a 30-minute interview via telephone or videoconference (Microsoft Teams) about your experience using the digital intervention. The interview will be audio-recorded if via telephone or video-recorded if via Microsoft Teams.
- Complete a short questionnaire.

Participation is entirely voluntary.

The researchers do not expect the questions to cause any harm or discomfort to you. There is a risk that some information you learn through the website might cause distress. If you experience feelings of distress because of participation in this study, 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 decline to take part in this research study. If you decide to take part and later change your mind, you may withdraw at any time without providing an explanation. To withdraw, please contact the Chief Investigator or you may just refuse to answer questions or leave the session or interview. You may choose whether any data collected up to the point of your withdrawal is securely destroyed or is included in the study.

Confidentiality and Privacy

Only researchers listed on this form have access to the individual information provided by you. Privacy and confidentiality will be always assured. 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 always protected. You will not be named, and your individual information will not be identifiable in any research products without your explicit consent.

No data, including identifiable, non-identifiable and de-identified datasets, will be shared, or used in future research projects without your explicit consent.

Data Storage

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

Recognition of Contribution / Time / Travel costs

If you would like to participate, in recognition of your contribution and participation time, you will be provided with a \$50 voucher. This voucher will be sent to you on completion of the interview.

How will I receive feedback?

On project completion, a short summary of the outcomes will be provided to all participants via email or published on Flinders University's website.

Ethics Committee Approval

The project has been approved by Flinders University's Human Research Ethics Committee (5886).

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 which is yours to keep. If you accept our invitation to be involved, please sign the enclosed Consent Form.

CONSENT FORM

Consent Statement

- I have read and understood the information about the research, and I understand I am being asked to provide informed consent to participate in this research study. I understand that I can contact the research team if I have further questions about this research study.
- I am not aware of any condition that would prevent my participation, and I agree to participate in this project.
- I understand that I am free to withdraw at any time during the study.
- I understand that I can contact Flinders University's Research Ethics & Compliance Office if I have any complaints or reservations about the ethical conduct of this study.
- I understand that my involvement is confidential, and that the information collected may be published. I understand that I will not be identified in any research products.

I further consent to:

- completing a questionnaire
- having my information video recorded
- having my information audio recorded (if interviewed over the phone)
- being contacted about other research projects

Signed:

Name:

Date: