Flinders University

PARTICIPANT INFORMATION SHEET
AND
CONSENT FORM

This project has been approved by **Flinders University's Human Research Ethics Committee** (HREC Approval Number 9940 and expires December 2027) and meets the requirements of the *National Statement on Ethical Conduct in Human Research*.

Title: What is the experience of stroke survivors leaving public health services once they have a NDIS plan?

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My name is Rachael and I am a Flinders University Masters student. I am undertaking this research as part of my degree. For further information, you are more than welcome to contact my supervisor. Their details are listed above.

Description of the Study

The proposed research study is a qualitative study, aimed at exploring the satisfaction of stroke survivors accessing NDIS services for the first time. Information will be collected via semi-structured interviews and analysed to understand the perspectives of stroke survivors in their journey. Prior to the interview, stroke survivors will be asked to complete a questionnaire about their stroke and involvement with rehabilitation or NDIS services.

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

Purpose of the Study
This project aims to find out the satisfaction of stroke survivors when accessing the NDIS after receiving rehabilitation.

Benefits of the Study
The sharing of your experiences will help to understand how clinicians can support stroke survivors in their journey, particularly between rehabilitation and long-term care services via the NDIS. This can also guide information provided to stroke survivors and their families when first discussing access to the NDIS and possible permanence of impairments.

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

- Complete a pre-interview questionnaire regarding your stroke and involvement with services, both health services and through the NDIS
- Attend a one-on-one interview with a researcher that will be audio recorded. The interview will take approximately one hour. This may be video recorded if completed via video call technology.

Participants are welcome to bring a support person, such as a family member, to the interview. They will not be asked questions to participate in the interview.

Potential Risks
Due to the nature of questions, you may find it upsetting or distressing to recount your experience of accessing services. If you wish to take a break or stop the interview at any time, you are able to do so without adverse outcomes.

Support Services
If you, or your support people, experience feelings of distress because of participation in this study, you can contact the following services for support:

- Lifeline: 13 11 14
- Stroke Line: 1800 787 653
- Beyond Blue: 1300 22 4636
- 13YARN: 13 92 76
- Carer Gateway: 1800 422 37

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 to have your data removed from the study or ask to cease the interview. Any data collected up to the point of your withdrawal will be securely destroyed and not used in the research.

Confidentiality and Privacy

Only researchers listed on this form have access to personal and sensitive information provided by you. Researchers will take all possible steps to ensure privacy and confidentiality will be adhered to at all times.

The research outcomes may be presented at conferences, written up for publication or used for other research purposes as described in this information form.

You will not be named, and your individual information will not be identifiable in any research products.

Data, including identifiable, non-identifiable and de-identified datasets, will not be shared with other research groups or used in future research projects.

Deidentified research data and transcripts may be entered into closed loop AI platforms to analyse themes of the research. Transcription will be undertaken by Microsoft Teams or one of the researchers.

Data Storage

The information collected will be stored securely at Flinders University following the University's Research Data Management Procedures.

Data may be stored temporarily on Flinders University's OneDrive with password protection, to allow collaborator access / version control during the study period.

Any identifiable data will be de-identified for data storage purposes, unless indicated otherwise.

At the conclusion of the research project, all data will be securely transferred to and stored at Flinders University (R: drive) for 12 months after the completion of the project. The Flinders University R: drive provides safe and secure storage and management of research data which meets the requirements of the Australian Code for the Responsible Conduct of Research.

Following the required data storage period above, all data will be securely destroyed according to Flinders University Research Data Management Procedures.

Study Feedback

On project completion, a short summary of the outcomes and research will be provided to all participants via email.

Ethics Committee Approval

The project has been approved by Flinders University's Human Research Ethics Committee (HREC Approval Number 9940).

Questions or Concerns About the Study

Specific questions regarding this research project can be directed to the research team on the following e-mail address: brag0026@flinders.edu.au

If you have any complaints or reservations about the ethical conduct of this study, please contact the Flinders University's Research Ethics, Integrity and Compliance Office via telephone (08) 8201 2543 or by emailing human.researchethics@flinders.edu.au and quoting the HREC Approval Number (HREC Approval Number 9940).

Thank you for taking the time to read this information sheet which is yours to keep.

Consent

If you accept our invitation to be involved, please sign the enclosed Consent Form and return via email to brag0026@flinders.edu.au

CONSENT FORM

Title: What is the experience of stroke survivors leaving public health services once they have a NDIS plan?
HREC Project Approval Number: 9940

Consent Options

☐ 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 on this e-mail address brag0026@flinders.edu.au 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 will be able to withdraw my data and information from this project.

☐ I understand that if I withdraw from the study my data will not be used for this research study

☐ I understand that the information I provide may be published. I understand that I will not be identified in any research products.

☐ I understand that my information may be entered into AI platforms such as MS Teams for transcription purposes or to analyse themes from the data.

☐ I understand that I can contact Flinders University's Research Ethics, Integrity and Compliance Office if I have any complaints or reservations about the ethical conduct of this study on human.researchethics@flinders.edu.au and quote HREC Approval Number 9940.

Regarding participation, I consent to:

☐ participating in an interview
☐ having my information audio recorded
☐ having my information video recorded

I further consent to:

☐ my data and information being used in this project only no more than 1 year after publication of the data

Signed:

Name:

Date: