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## PARTICIPANT INFORMATION SHEET AND CONSENT FORM – Family and Carers

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**Title:** Goal setting to support stroke and brain injury rehabilitation and recovery

### Chief Investigator

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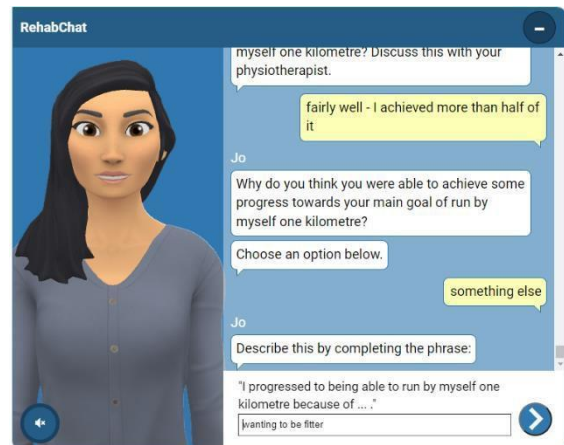
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College of Nursing and Health Sciences  
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### Description of the study

You are invited to take part in this project investigating goal-setting in stroke and brain injury rehabilitation. You are able to participate because you provide support as a family member or carer for an adult with stroke or brain injury, and you are aged 18 years or older.

This project aims to understand the experiences of setting and working towards goals in recovery following brain injury and stroke. The second aim of this project is to gather feedback on RehabChat – an application that was co-designed by people with brain injury and clinicians to support goal setting to better understand if and how RehabChat could be used in practice. RehabChat can be used on a handheld tablet device or computer. An example of what a RehabChat interaction looks like is included in the image here. This project is supported by Flinders University, College of Nursing and Health Sciences and College of Science and Engineering. This project has received funding from the Caring Futures Institute and Lifetime Support Authority.



### Purpose of the study

This project aims to find out about the experiences of setting goals and working toward goals during rehabilitation and recovery from brain injury and stroke. The project also aims to gather information about how technologies such as RehabChat could be used to support goal setting activities during rehabilitation and recovery.

## Benefits of the study

The sharing of your experiences will help to provide more information about how goal setting is used in recovery following brain injury and stroke. While you may not directly benefit from taking part in the study, sharing your experiences will help the research team to understand how technologies like the RehabChat application might be used in the recovery journey and to plan future research.

## Participant involvement and potential risks

If you decide you would like to participate in the research study, you will be asked to sign the consent form. Once the consent form is signed, you will be asked for your preference of time and location for the data collection session. This session will last for 60-90 minutes and be conducted at one of the participating data collection sites across Adelaide most convenient to you.

In the data collection session:

- You will be asked some questions about your experience supporting a person with stroke or brain injury setting goals as part of their recovery.
- You will be asked to use the RehabChat chatbot designed to support goal setting and share your thoughts about the experience.
- You will be asked for permission to record the conversation so that the information can be used after the session to better understand goal setting experiences and if and how technology may be used to support goal setting in recovery after brain injury or stroke.
- You may choose to bring a family member, friend, or support person to the session with you.

The researchers will ask questions about your experience supporting a person with stroke or brain injury with setting goals during their rehabilitation and recovery. Thinking and talking about some of these things may cause feelings of discomfort or frustration. If you experience feelings of discomfort, distress or frustration during participation in this study, please let the researcher know and we can stop the discussion and take a break or we can finish the session at that time. If you experience any feelings of distress after participating in the project, you can also contact the following services for support:

- Lifeline - Lifeline provides crisis support 24 hours a day, seven days a week. Call Lifeline on 13 11 14. Visit [lifeline.org.au](https://lifeline.org.au)
- Stroke Line – For non-urgent stroke specific support StrokeLine is available Monday to Friday 9am to 5pm, Eastern Standard Time (closed on public holidays). Phone: 1800 787 653 Email: [strokeline@strokefoundation.org.au](mailto:strokeline@strokefoundation.org.au)
- Synapse – For non-urgent brain injury information and referral Synapse is available Phone: 1800 673 074 or online at <https://synapse.org.au/our-services/information-and-referral/>

## Withdrawal Rights

Participation is voluntary. You may decide not to take part in this research study. If you decide to take part and later change your mind, you may stop and withdraw (finish) at any time. There is no need to give a reason. If you want to stop during the session, please let the researcher know and they will stop. If you decide later, after the session, that you want to withdraw your data, that may be possible up until we have started to analyse the data. Once we start looking at all the data, we will no longer be able to separate your information out from the rest of the information collected. The researcher will give you more information about when we will start looking at the data so you will know the time when we will be unable to remove your data – up until that time, you can contact the research team and request that your data be removed from the study.

## Confidentiality and Privacy

Only researchers listed on this form have access to the individual information provided by you. Your privacy and confidentiality is important to the research team and will be respected and protected. We will be using transcription services – such as Microsoft Transcribe, Microsoft Teams, or Otter.ai (Otter.ai's privacy policy is available here if you would like more information (<https://otter.ai/privacy-security>) – to turn the audio recording of our conversation into text so that we can analyse it. We will not be sharing your name or personal

information with the transcription service and will delete the recording once it has been analysed. These transcription services do not use data for anything else. 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 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 will 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**

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 provided to you after the data collection session.

### **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 provide your email or address to the researcher at the data collection session if you would like to receive this summary.

### **Ethics Committee Approval**

The project has been approved by Flinders University's Human Research Ethics Committee (HREC project 6512).

### **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 and Compliance Office team either via telephone (08) 8201 2543 or by emailing the Office via [human.researchethics@flinders.edu.au](mailto: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.

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## CONSENT FORM for Community Participant

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**Title:** Goal setting to support brain injury rehabilitation and recovery  
(HREC project number 6512)

### 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 and 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 understand that I will be able to withdraw my data and information from this project up until the date that the researchers start analysing the data.

I further consent to attending one data collection session where I will be:

- completing a questionnaire
- participating in an interview
- using the RehabChat app
- having my information audio recorded
- agreeing to my data and information being used only in this project and stored for no more than 5 years after publication of the data

**Signed:**

**Name:**

**Date:**