

PARTICIPANT INFORMATION SHEET – CAREGIVERS / SUPPORT PERSONS

Title of Project: Supporting Young Stroke Survivors Through Engaging Messaging (SYSSTEM)

Research team

Investigators	Name	School	Email/Contact number
Chief Investigator	Dr Marie-Louise Bird	School of Health Sciences University of Tasmania	marie-louise.bird@utas.edu.au 61 3 63245497
Associate Investigators	Dinah Amoah (PhD candidate)	School of Health Sciences University of Tasmania	Dinah.amoah@utas.edu.au +61 473866560
	Dr. Mathew Schmidt	School of Health Sciences University of Tasmania	matthew.schmidt@utas.edu.au +61 3 6226 4224
	Dr. Sarah Prior	Tasmanian School of Medicine University of Tasmania	sarah.prior@utas.edu.au +61 36430 1632
	Dr. Carey Mather	School of Nursing University of Tasmania	carey.mather@utas.edu.au +61 3 6324 3149

1. Invitation

You are invited to participate in a nationwide research project. This project is designed to understand the experiences of young stroke survivors, aged 18-30 years, who had a stroke before they turned 25. We will also talk to caregivers and health care professionals about the unmet needs of young stroke survivors. This project will contribute to new knowledge about how technology may support young stroke survivors.

2. What is the purpose of this study?

This study aims to find out how best to improve participation and quality of life for young stroke survivors using different forms of technology.

3. How is the study being funded?

The project is co-funded by TasCare and the Tasmania College of Health and Medicine Graduate Research scholarship.

4. Why have I been invited to participate?

You have been invited because you are a carer or caregiver of a young (< 30 years old) stroke survivor who had stroke when they were <25 years. Your participation in this research is entirely voluntary. There are no consequences if you decide not to participate at any stage of this research, your relationship with your healthcare provider or with the University of Tasmania will not change.

5. What will I be asked to do?

We will ask you to be involved in our research in a number of ways:



UNIVERSITY of
TASMANIA
AUSTRALIA

- As a support person for a young stroke survivor during a one-on-one interview or focus group session AND/OR
- In a one-on-one interview as a caregiver providing information about your own experience working with young people with stroke OR
- In a focus group session for caregivers who work with young people with stroke.

Each of these discussions will be audio-recorded. We expect that each of the interview or focus group sessions will last between 30-90 minutes, depending on what you would like to talk to us about. We will ask you to provide some information such as your age, relationship to the stroke survivor, occupation, how long you have supported young people with stroke, stroke survivors' problems/needs, what you consider as important to address their needs, and the role of technology in improving their quality of life. Your data will not be identifiable and will be collected anonymously. If you choose to participate in a focus group, we will offer you a summary of the discussion points from the focus group for validation and ask that you provide any feedback within 7 days.

6. Are there any possible benefits from participation in this study?

You will receive a gift card to the value of \$50 (AUD) for participation. Also, this study will increase our knowledge on the unmet needs of young people with stroke and how these needs can be met, and results may help improve the quality of life for young stroke survivors in the future.

7. Are there any possible risks from participation in this study?

Sometimes talking about your personal experiences caring for young stroke survivors can trigger memories that may be upsetting. If you feel overwhelmed, we will be guided by any decision by you to stop any discussions or take a break as needed. We will try to provide a supportive environment by checking in with you regularly to ensure you are comfortable to continue, as well as providing referral details for you to seek further information about support if you need it, from **StrokeLine: 1 800 787 653** or LifeLine counselling services 13 11 14.

8. What if I change my mind during or after the study?

You are free to withdraw or change your mind about being involved at any time, up to 2 weeks after an interview or focus groups without providing an explanation. However, you will not be able to withdraw your data after two weeks as our data analysis might have commenced, and your information may already be combined with other information.

9. What will happen to the data when this study is over?

All your information will be treated with respect and confidentiality and used only for the purpose of this research. Your name or any other identifying information will not be used in publications or reports but some of your phrases may be quoted using codes for identity. Participants in the focus group sessions will be requested to keep all discussions confidential. Data from interviews and focus groups will be stored in a secured password-protected server at the University of Tasmania which



will only be accessible to the researchers of this project. Data generated will be kept for a minimum of 5 years from the date of thesis completion and destroyed at the end of the 5 years.

10. How will the results of the study be published?

The results of this research may be disseminated through publications (policy briefs, peer-reviewed journal articles), presentations at national and international conferences, university seminars, and university open access repositories as appropriate. You will not be identifiable in any publication.

11. What if I have questions about this study?

If you have any queries, concerns, or issues with this study, please feel free to contact us on the details above. If you have questions about the project, please contact the Chief Investigator Dr. Marie-Louise Bird at marie-louise.bird@utas.edu.au

This study has been approved by the University of Tasmania Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study, you can contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 6254 or email human.ethics@utas.edu. The Executive Officer is the person nominated to receive complaints from research participants. Ethics approval number is **H0026242**

12. How can I agree to be involved?

By acknowledging that participation is voluntary and that you have read this information sheet, please sign either the electronic or hardcopy consent form to agree to partake in either the interview or focus group session. Please feel free to contact the research team with any questions or concerns.

You may keep this Information Sheet. Thank you for your time

Title of research project: Supporting Young Stroke Survivors Through Engaging Messaging (SYSSTEM)

PARTICIPANT CONSENT FORM – Caregivers / Support Persons

Research team

Investigators	Name	School	Email/Contact number
Chief Investigator	Dr Marie-Louise Bird	School of Health Sciences University of Tasmania	marie-louise.bird@utas.edu.au 61 3 63245497
Associate Investigators	Dinah Amoah (PhD candidate)	School of Health Sciences University of Tasmania	Dinah.amoah@utas.edu.au +61 473866560
	Dr. Mathew Schmidt	School of Health Sciences University of Tasmania	matthew.schmidt@utas.edu.au +61 3 6226 4224
	Dr. Sarah Prior	Tasmanian School of Medicine University of Tasmania	sarah.prior@utas.edu.au +61 36430 1632
	Dr. Carey Mather	School of Nursing University of Tasmania	carey.mather@utas.edu.au +61 3 6324 3149

By signing below, I confirm that I have read and understood the information sheet and in particular:

- I understand that my involvement in this research will include participating in either a one-on-one interview as a support person or a focus group or interview as the main participant. Each of these interviews is expected to last between 30-90 minutes
- I understand that the research may include audio recording of interviews and focus group discussions
- I agree to participate

As a support person for a young stroke survivor

In a Focus group as the main participant

In an Interview as the main participant

- I understand that there may be minimal risk of experiencing emotional or psychological distress during my participation in the study. However, at any time during the interview, I may stop or withdraw and be referred to stroke support **Stroke Line:** 1 800 787 653 for advice. I also understand that in the case of communication impairment, a speech pathologist will be available to facilitate the interview or focus group where necessary
- Any questions that I have asked have been answered to my satisfaction



UNIVERSITY of
TASMANIA
AUSTRALIA

- I understand that all study data will be securely stored on the University of Tasmania server and this data will be destroyed 5 years from the date of thesis completion
- I understand that the results of the study will be published so that I cannot be identified as a participant
- I understand that my participation in this research is voluntary

- I understand that I am free to withdraw at any time, without explanation or penalty
- If I wish, I may request that any data I have supplied be withdrawn from the research up to 2 weeks post-interview or focus group
- I understand that I will not be able to withdraw my data after 2 weeks as data collation and analysis might have started and data will no longer have my name attached to it
- I agree to participate in the study

Name	
Signature	
Date	

Statement by Researcher

I have explained the project and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation.

If the researcher has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

The participant has received the Information Sheet where my details have been provided so participants have had the opportunity to contact me prior to consenting to participate in this project.

Name	
Signature	
Date	