**PARTICIPANT INFORMATION SHEET**

**Title of Project**: Understanding how to use technology to improve the quality of life of young people after stroke

Research team

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| **Investigators** | **Name** | **School** | **Email/Contact number** |
| Chief Investigator | Dr Marie-Louise Bird | School of Health SciencesUniversity of Tasmania | marie-louise.bird@utas.edu.au61 3 63245497 |
| Associate Investigators | Dinah Amoah (PhD candidate) | School of Health SciencesUniversity of Tasmania | Dinah.amoah@utas.edu.au+61 3 6324 5441 |
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## Invitation

You are invited to be part of a nationwide research project. This project aims to understand the experiences of young stroke survivors, and how these experiences could be improved with new or changed existing technology-based resources, such as websites or apps on your phone or computer.

## What is the purpose of this study?

This study aims to find out how young stroke survivors can be best supported in their recovery and any ongoing challenges by using technology-based resources.

## How is the study being funded?

This project is co-funded by the TasCare PhD Scholarship and the Tasmanian College of Health and Medicine Graduate Research Scholarship programs.

The TasCare PhD Scholarship was established by funds gifted to the University of Tasmania in 2019 by the TasCare Society for Children Inc, prior to it ceasing to operate in 2020. The fund is currently being administered by the University of Tasmania.

## Why have I been invited to participate?

You have been invited because you are a young (18- 30 years old) stroke survivor who had stroke before you turned 25. Being part of this research is entirely up to you, you do not have to be involved if you do not wish to. There are no consequences if you decide not to be involved at any stage of this research, your relationship with your healthcare provider or with the University of Tasmania will not change.

##  What will I be asked to do?

If you agree to be involved in this research, you will be asked to complete a short (up to 15 minutes) anonymous online survey or a telephone survey if you find using the website a bit hard. If you agree to participate over the phone, the signed consent form is expected to be returned within 1 week either via email or post depending on your preference. Survey conducted over the phone will be audio recorded and data entered directly into the REDCap software. The REDCap software is a web platform for collecting and storing research data. You will be asked to provide responses to questions about yourself (age, location) and then questions about your stroke and recovery from your stroke. We also want to know whether technology might be a good way to support young people who have had a stroke, so we have some questions around this as well. We will not know who has completed the survey, all of the information will be anonymous. You will also be asked if you would like to take part in the next stage of the study (intervention). The intervention part of the study is expected to start in the second half of 2023.

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

There may be no direct benefits to you as a person in this research. However, the outcomes of this study may have some benefit for you if you use the resources we deliver in the future. We expect that future young stroke survivors in Australia will benefit from our findings and our deliverables in the form of improved resources to support recovery and activities of daily living. When you finish the survey, you can also choose to go into a draw to win one of four gift vouchers valued at $50. After completion of the study, winners will be randomly selected from all eligible entrants via an online tool called a random name picker. All winners will be contacted by their nominated email address.

## Are there any possible risks from participation in this study?

We think any risk in this study is low, however, writing or talking about your health and medical information about stroke may cause you some discomfort or distress. If you experience emotional discomfort, we recommend that you contact the StrokeLine: 1 800 787 653 or LifeLine counselling services (13 11 14). We have also provided these details within the survey if you need support as you are working through the questions.

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

You may withdraw at any time during completion of the survey without any consequences. If you start the survey and complete less than half, you will be considered to have withdrawn from the survey and any information you have given will be removed. If you complete more than half, your information will be included. Once you submit the survey, it will be impossible to take back your answer as we do not have any names on the surveys.

## 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 study. Your contact details will be removed from our system following the draw of the $50, if you choose to enter this draw. All data will be collated and reported collectively. Data from the survey will be stored in a secure password-protected server at the University of Tasmania which will only be accessible to the researchers of this project. All data including the details of participants interested to partake in the intervention phase will be kept for a minimum of 5 years from the date of thesis completion and destroyed at the end of the 5 years, as per the University of Tasmania Research Data Management Policy (https://utas.libguides.com/ResearchData/retention ).

1. **How will the results of the study be published?**

The results of this research may be shared through publications (Policy briefs, peer-reviewed journal articles), presentations at national and international conferences, University seminars, and University open access libraries as appropriate. You will not be identifiable in any publication as we will not know who have completed the surveys.

## 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 or Dinah Amoah at dinah.amoah@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.au.

The Executive Officer is the person nominated to receive complaints from research participants. Ethics approval number is **H0028759.**

1. **How can I agree to be involved?**

By acknowledging that participation is voluntary and that you have read this information sheet, please respond "Yes" at the consent section electronically or complete a hardcopy consent form to be involved. Please feel free to contact the research team any time if you have questions or concerns. Please feel free to share the link to this survey with other young stroke survivors that you know.

 **Thank you for your time**

**Title of research project:** Understanding how to use technology to improve the quality of life of young people after stroke

**PARTICIPANT CONSENT FORM**

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| Dr. Carey Mather | School of NursingUniversity of Tasmania | carey.mather@utas.edu.au+61 3 6324 3149  |

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

* I understand that my involvement in this research will involve completing a short anonymous online survey and I will be asked to provide some information about myself and some information about my stroke and needs after my stroke. The survey is expected to last for 15 minutes.
* I understand that there may be a small risk of feeling distressed during the survey. If I feel this way, I may stop or withdraw and I have the option to contact the StrokeLine: 1 800 787 653 or LifeLine counselling services 13 11 14 with details provided on the questionnaire as well
* I also understand that I have the option to complete the survey over the phone if I find using the website a bit hard.
* I understand that my responses will be audio recorded if survey is done over the phone
* I understand that all study information 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 and I do not have to be involved
* I understand that I am free to withdraw at any time without explanation or penalty by closing the browser before submitting the survey
* I understand that once I submit the survey, it will be impossible to retract my answer as the information is not identifiable

I agree to take part in the study

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| Name |  |
| Signature |  |
| Date |  |

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| **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. |

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| --- | --- |
| Name |  |
| Signature |  |
| Date |  |