



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Stroke Aid

Liam Lo Cascio, Student Investigator

1. What is the research study about?

You are invited to take part in this research study. The research study aims to develop further understanding about stroke and stroke related impairments. Resulting insights will assist to create a product which makes the lives of stroke survivors easier. You have been invited because you have first-hand experience into stroke and its management, and your contact details were obtained online.

2. Who is conducting this research?

The study is being carried out by the following researcher: Liam Lo Cascio, UNSW – Art Design and Architecture.

3. Inclusion/Exclusion Criteria

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking to recruit people who meet the following criteria:

- Experience of life with Stroke OR
- Experience in the treatment or management of stroke

4. Do I have to take part in this research study?

Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

If you decide you want to take part in the research study, you will be asked to:

- Read the information carefully (ask questions if necessary);
- Sign and return the consent form if you decide to participate in the study;
- Take a copy of this form with you to keep.

5. What does participation in this research require, and are there any risks involved?

- If you decide to take part in the interview, you will be asked to participate in an online or face to face setting. You will be asked questions about stroke and stroke related topics. It should take approximately 20-30 minutes to complete.

To ensure we collect the responses accurately, we seek your permission to digitally record the interview using an audio and video recording. If you would like to participate but do not wish to be recorded, you will need to discuss the options for your participation with the research team.

- If you decide to take part in the research study, the research team will ask you to film everyday activities performed in your home. The recordings will then be reviewed with the research team to analyse the events of the recording. It should take approximately 30 minutes at home to complete the task and 30 minutes online to discuss the findings.

If you experience discomfort or feelings of distress while participating in the research and you require support, you can stop participating at any time. You can also tell a member of the research and they will provide you with assistance.

6. What are the possible benefits to participation?

We hope to use information we get from this research study to benefit others who suffer from stroke related disabilities to live a more comfortable and independent life.



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7. What will happen to information about me?

By signing the consent form you consent to the research team collecting and using information about you for the research study. Your data will be kept for 5 years after the project's completion. We will store information about you in a non-identifiable format at The UNSW Data Archive

Your information will only be used for research purposes to gain insight into stroke and its surrounding topics. Any information provided will be summarised or produced as a direct quote. This research report will be submitted as part of a capstone thesis.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

8. How and when will I find out what the results of the research study are?

The research results will be compiled in a report as part of an assignment for UNSW. This will be done in a way that will not identify you.

If you would like to receive a copy of the results you can let the research team know by including your details in the space provided in the consent form.

9. What if I want to withdraw from the research study?

If you do consent to participate, you may withdraw at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document. Alternatively, you can ring the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney.

If you decide to leave the research study, the researchers will not collect additional information from you. Any identifiable information about you will be withdrawn from the research project.

10. What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:



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Research Team Contact Details

Name	Liam Lo Cascio
Position	Student Investigator
Email	l.lo_cascio@student.unsw.edu.au

What if I have a complaint or any concerns about the research study?

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

Complaints Contact

Position	UNSW Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference Number	HC16088



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Consent Form – Participant providing own consent

Declaration by the participant

- ☐ I understand I am being asked to provide consent to participate in this research study;
- ☐ I have read the Participant Information Sheet, or someone has read it to me in a language that I understand.
- ☐ I understand the purposes, study tasks and risks of the research described in the study;
- ☐ I understand that the research team will audio/video record the interviews; I agree to be recorded for this purpose.
- ☐ I provide my consent for the information collected about me to be used for the purpose of this research study only.
- ☐ I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- ☐ I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- ☐ I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only;

Name: _____

Address: _____

Email Address: _____

- ☐ I understand that I will be given a signed copy of this document to keep;

Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

Declaration by Researcher*

- ☐ I have given a verbal explanation of the research study, its study activities and risks and I believe that the participant has understood that explanation.

Researcher Signature*

Name of Researcher (please print)	Liam Lo Cascio
Signature of Researcher	
Date	

*An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.

Note: All parties signing the consent section must date their own signature.



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Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales. In withdrawing my consent I would like any information which I have provided for the purpose of this research study withdrawn.

Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

The section for Withdrawal of Participation should be forwarded to:

CI Name:	Prof Oya Demirbilek
Email:	o.demirbilek@unsw.edu.au