**A-LISTS Participant Information Sheet for Co-design Scoping Survey**




**Australian Stroke Clinical Registry- LIfe after Stroke with Tailored Support (A-LISTS)**

**Project Title:** Australian Stroke Clinical registry- LIfe after Stroke with Tailored Support (A-LISTS)

**Protocol Number:**  HREC/86507/Austin-2022

**Project Sponsor:** TheFlorey Institute of Neuroscience and Mental Health.

**Funded by:** Medical Research Future Fund 2020 Cardiovascular Health Mission

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| **Coordinating Principal Investigator:** Professor Dominique Cadilhac, Head of Public Health, Stroke Division, Data Custodian Australian Stroke Clinical Registry, The Florey Institute of Neuroscience and Mental Health, Victoria**Phone:** (03) 9035 7032**Email:** dominique.cadilhac@florey.edu.au **Chief Investigators:** Prof Dominique CadilhacProf Sandy Middleton, Prof Tim Kleinig, Prof Rohan Grimley, A/ Prof Monique Kilkenny, Dr Joosup Kim **Associate Investigators:** Prof Natasha Lannin, Dr Lisa Murphy, Mrs Jennifer Cranefield, Prof Vincent Thijs, Ms Katherine Jaques, Ms Louise Kelly, Prof Julie Bernhardt |   |

**Background:** Many people living with stroke have ongoing disability and report extreme problems in different domains of quality of life up to six months following stroke. Of concern is that the majority have also reported that their long-term needs are unmet two years after stroke. We are seeking your help to co-design a supplementary follow-up service for people registered in the Australian Stroke Clinical Registry who report extreme problems or unmet needs within six months of stroke. Our project has received seed funding from the Medical Research Future Fund. The Australian Stroke Clinical Registry ([www.auscr.com.au](http://www.auscr.com.au)) is undertaken in 63 hospitals across Australia. The primary purpose is to monitor the quality of care in hospital, and we also collect health outcome data between 90-180 days after admission. The individual patient outcome data are available for hospital staff to download, or they can access a summary report of the aggregated patient data for their hospital. We now seek to design and trial the feasibility of a hospital-initiated follow-up service to act on the data for people who respond to having extreme problems or unmet needs. Our mechanism for doing this will be with the hospitals that have provided patient data for the registry, as we do not collect information about general practitioners the patient is seeing.

**What is the purpose of this research?**

The A-LISTS study has two stages: i) an intervention design stage; and ii) a randomised controlled pilot trial to test the feasibility of providing a tailored follow-up support service for people living with stroke (aged 18 years or over) who are registered in the Australian Stroke Clinical Registry and meet the inclusion criteria for the service. We hope to learn whether this type of supplementary follow-up service, is feasible and acceptable in helping improve health outcomes or reducing unmet needs for people living with stroke.

**What do I have to do?**

We would like your input for the intervention design stage. Please complete the online survey using the link provided. This will take approximately 30 minutes to complete. [Qualtrics Survey | A-LISTS co-design survey](https://melbourneuni.au1.qualtrics.com/jfe/form/SV_cMDYbqOroqkPu7k)

**Do I have to take part in this research project?**

Participation in any research project is voluntary. If you do not wish 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 project at any stage. Please note that we will retain any partially completed survey data should you decide to not proceed with fully completing the online survey.

Your decision whether to take part or not to take part, will not affect your relationship with those involved in the study or your relationship with The Florey Institute of Neuroscience and Mental Health.

**What are the benefits?**

We cannot guarantee that you will receive any direct benefits from completing the survey, but the results will be used to help others, by helping us use the stroke registry data in a proactive manner with the aim of improving the lives of people with stroke.

**What are the risks?**

Apart from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this survey. If you do have any concerns about your participation when completing the survey then please contact us so we can discuss the best way to manage your concerns.

**What will happen to the survey information?**

All information obtained relating to this survey will be kept confidential. We will collect and store the information securely on the Florey infrastructure technology network hosted by the University of Melbourne which meets industry standards for security including two-factor authentication procedures. Your information will be grouped with other participants’ information for reporting purposes, such as in research publications or conference presentations. This means you will not be identified in any type of publication from this study. Any quotes that may be used will be attributed to a role (e.g., physiotherapist, patient representative). As per good research practices, we will keep your information for seven years after the project is completed. After this time, the electronic data will be deleted.

**Consenting to participate in the study and withdrawing from the research**

Being in this study is completely voluntary and you do not have to take part. Submitting your completed questionnaire is an indication of your consent to participate in the study. You can withdraw your responses any time before you have submitted the questionnaire. Once you have submitted your completed questionnaire, your responses cannot be withdrawn because they are anonymous. Therefore, we will be unable to tell which questionnaire is yours.

**Will I hear about the results of the survey?**

A summary of the results of the survey can be made available to you at the end of stage 1 of the study. If you would like a copy, this option will be provided in the online survey if you are willing to register your email address. The email address will be kept in a separate section of the database and will not be linked to your survey answers.

**Who is organising and funding the research?**

The Medical Research Future Fund 2020 Cardiovascular Health Mission.

**Who can I contact for questions or want more information?**

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| **Name/Organisation** | **Position** | **Telephone** | **Email** |
| Andrew Ross The Florey Institute  | Project Coordinator | 03 9035 7067 | andrew.ross@florey.edu.au |
| Prof Dominique CadilhacThe Florey Institute | Coordinating Principal Investigator | 03 9035 7032 | dominique.cadilhac@florey.edu.au  |

**What if I have a complaint?**

If you have a complaint about any part of this study, please contact:

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| **Ethics Reference Number** | **Position** | **Telephone** | **Email** |
| HREC/86507/Austin-2022 | Complaints Officer  | (03) 9496 4090  | research@austin.org.au |