

**Explanatory Statement – Carers**

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| **Title** | Healthcare service experiences of young adults with stroke |
| **Project Number** | 37473 |
| **Project Sponsor** | Monash University |
| **Principal Investigator** | Professor Natasha Lannin |
| **Position** | Occupational Therapist, Professor |
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| **Email** | [Natasha.lannin@monsah.edu](mailto:Natasha.lannin@monsah.edu) |

**Part 1 What does my participation involve?**

**1 Introduction**

You are invited to take part in this research study. This is because you support a person who has had a stroke in the past ten years who is currently aged between 18 and 55 years old and living in Australia. You are invited to participate as you have played a role in supporting access to healthcare services for their stroke-related needs, and we want to learn from your experiences in how we can improve services for young adults and their families.

This Explanatory Statement tells you about the research study and what participating in the study involves. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don’t understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative or friend.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

* Understand what you have read
* Consent to take part in the research project
* Consent to the tests and research that are described
* Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

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

This research project seeks to understand your experience in supporting a younger adult with stroke in accessing health services to meet their stroke-related needs. As a carer or supporter who has helped a young adult to access services, your experiences will provide important information about what has worked well both for them and for yourself as a carer (or supporter) and why, as well as what has not worked well. We want to know how you think health services could have better met the needs of the person you support. Our team will take what we learn from your experiences, as well as the experiences of patients and clinicians, to design a new Young Stroke Service that will better meet the needs of young adults with stroke.

**3 What does participation in this research involve?**

You are invited to participate by completing questionnaires that ask about who you are, the person you support, the types of services that you have supported them to access, and your experiences in helping them access those services. About 10 people will also be asked to participate in an interview so that we can talk in more detail about healthcare preferences for younger adults who have had a stroke.

If you participate in the study, we will send you a copy of the questionnaire in a format of your preference. This will include the option to complete the questionnaire on the internet or in hard copy. If you complete a paper copy of the questionnaire, we will give you a reply-paid envelope to return it to us. Otherwise you can take photos of it, or scan it, and email it back to us. The questionnaire will take up to one hour to complete.

If you also participate in an interview, you can do that on the telephone, using Zoom, or in person at Alfred Health. Interviews will be completed with a member of the research team at a time that is convenient to you. The interviews are expected to take about one hour. The interview will be informal and flexible, as our main aim is to hear about your preferences for how services should be provided for young adults after a stroke. We also want to know what you think about a new service that will be providing supports to young adults after stroke. You can ask for a copy of the interview questions before agreeing to participate.

We would like to record the audio from the interview so that we have a good record of what you shared with us. The recordings will be transcribed within 4 weeks of the interview, and the audio recordings will be deleted after we have finished the analysis. Names and other sensitive information will be removed from the transcripts as we want to protect your identity and any confidential information that you may share. If you wish to receive a copy of your interview transcript, please notify the researchers listed at the start of this document.

**4 What are the possible risks and disadvantages of taking part?**

You will not receive any personal benefits from taking part in this project. However, participating in the project will assist us in understanding key experiences, values and preferences of people who have had a stroke and those who support them. The findings will be used to help develop a new service for young adults. There are no costs to you from participating in the project. People who participate in the questionnaires will be given a $20 gift voucher to thank them for their time, and people who participate in the interviews will be paid $50 for their time.

Participation in an interview should involve no physical or mental discomfort, and no risks beyond those of everyday living. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the Principal Investigator (Professor Natasha Lannin).

If you do become distressed during an interview, the interview will stop immediately and you will be able to discontinue your participation. You will also be directed to contact your doctor who may be able to arrange for you to access counselling or support at no cost to you through Medicare. We may also suggest other support services that could be relevant to you. If a serious event or emergency occurs during an interview, you will be instructed to end the connection and to contact the relevant emergency service. If this is not possible, the interviewer will do this on your behalf.

**5 What if I withdraw from the research project?**

Participation in any research project is voluntary. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect the routine treatment of the person you are caring for, your relationship with the clinicians treating them, or your relationship with Alfred Health or Monash University. If you wish to withdraw, please contact the researcher listed on this form. In the case of withdrawal, all data pertaining to you will be destroyed if it has not yet been included in analysis. However, once we commence analysing the interview transcripts it will not be possible to remove your information, and the data will have to be retained.

**Part 2 How is the research project being conducted?**

**6 What will happen to information about me?**

All questionnaire responses will be given a unique code so that your identity is not linked to your answers. All interview responses will be altered so that they do not include your name, or the names of other people or specific services. Data will be reported in a way that it will not be possible to identify individual participants, and all information will remain confidential. Your information will only be used for this research project and it will only be disclosed with your permission, except as required by law. Only members of the research team will have access to your data. Interview recordings will be stored and transferred using a secure process that protects your information.

It is anticipated that the results of this research project will be published and/or presented in a variety of ways. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your permission.

Data will be stored for 7 years. All data will be kept in a non-identifiable format. All identifying information recorded will be removed from transcription and files, and all files will be stored in password protected computer files that only the research team will have access to. That means we will remove your name and contact details from the data.

In accordance with relevant Australian and state privacy and other relevant laws, you have the right to request access to your information collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please contact the study team member named at the end of this document if you would like to access your information. You will be given the chance to provide feedback on the study findings before they are finalised.

Outcomes from the project will be summarised and presented at conferences. It is anticipated that we will also publish the findings in health journals. A summary of the findings will be provided to participants. We anticipate that this summary will be available at the end of 2023 when the research project is completed.

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

This research is being conducted by Professor Natasha Lannin and sponsored in Australia by Monash University (sponsor). It is funded by the Medical Research Future Fund (MRFF).

**8 Who has reviewed the research project?**

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of Monash University. This project will be carried out according to the NHMRC National Statement on Ethical Conduct in Human Research (2007) and the Note for Guidance on Good Clinical Practice (CPMP/ICH-135/95). This statement has been developed to protect the interests of people who agree to participate in human research studies.

**9 Further information and who to contact**

The person you may need to contact will depend on the nature of your query.

**Research contact person**

If you want any further information concerning this project, you can contact:

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| **Name** | Professor Natasha Lannin |
| **Position** | Principal Investigator |
| **Telephone** | [Natasha.Lannin@monash.edu](mailto:Natasha.Lannin@monash.edu) |
| **Email** | 0417 135 153 |

**Complaints contact person**

Should you have any concerns or complaints about the conduct of the project, you can contact:

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| **Position** | Executive Officer |
| **Office** | Monash University Human Research Ethics Committee (MUHREC)  Room 111, Chancellery Building D, 26 Sports Walk, Clayton Campus Research Office  Monash University VIC 3800 |
| **Telephone** | [muhrec@monash.edu](mailto:muhrec@monash.edu) |
| **Email** | 03 9905 2052 |