

**Explanatory Statement – Clinicians**

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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 of Neuroscience |
| **Telephone** | 0417 135 153 |
| **Email** | natasha.lannin@monash.edu |

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

**1 Introduction**

You are invited to take part in this research study. This is because you are currently working in a setting that supports or provides healthcare for young adults who are 18 to 45 years of age in Australia.

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.

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 providing or supporting the provision of healthcare services to people with stroke aged 18-45 years. As someone who supports healthcare delivery, your experiences will provide important information about what works well and why, as well as what makes it difficult to meet the needs of young adults with stroke. We want to know how you think health services could better meet the needs of younger adults who have had a stroke. Our team will take what we learn from your experiences, as well as the experiences of patients, families and carers, to design a new Young Stroke Service that aims to help meet the needs of young adults with stroke.

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

Clinicians are invited to participate by completing questionnaires that ask them to provide some information about themselves and the service that they currently work in (or that they previously worked in), and their experiences in providing those services. The questions will explore clinician perceptions of the accessibility, quality and patient-centredness of stroke-related health services. There will be the opportunity to explain how clinicians think the new Young Stroke Service should be designed to best meet the needs of young adults with stroke, and how the service should integrate or collaborate with existing services. Up to 15 clinicians, and other key stakeholders whose work supports the monitoring, funding or development of rehabilitation services for adults with stroke will also be asked to participate in an interview so that we can talk in more detail about your perspectives on healthcare service delivery for younger adult.

Clinicians who participate in the study will be sent a copy of the questionnaire to be completed on the internet, in hard copy or by telephone interview. If the questionnaires are completed in hardcopy a reply-paid envelope will be provided to return it to us. Otherwise participants 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 participate in an interview, you can do that on the telephone, using Zoom, or in person at Monash University or 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 perspectives on 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 share with us. The recordings will be transcribed within 4 weeks of the interview. The audio recordings will be deleted after we have finished the study. Names and other personal 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 let the researchers listed at the start of this document know.

**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 provide, monitor, design or fund services to younger people who have had a stroke. The findings will be used to help develop the Young Stroke Service. There are no costs to you from participating in the project. 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). People who participate in the interviews will be given the chance to go in the draw to win one of four $50 gift vouchers in thanks for their time.

**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 at any stage. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect 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.

**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. It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication or presentation, information will be provided in a way that you cannot be identified, except with your permission. Interview recordings will be stored and transferred using a secure process that protects your information.

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. 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, and published 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) and is being 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** | N.Lannin@alfred.org.au  |
| **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  |
| **Email** | 03 9905 2052 |