**EXPLANATORY STATEMENT [Page one of the Qualtrics Survey]**

**Project ID: 41443
Project title: Measuring Arm and Hand Improvements: What Matters Most to Stroke Survivors?
Chief Investigator’s name: Professor Natasha Lannin**

Welcome to the “Measuring Arm and Hand Improvements” Survey.

This survey is being conducted by the Department of Neuroscience at Monash University and led by Professor Natasha Lannin (Lab Head, Brain Recovery and Rehabilitation Group). We are seeking feedback and opinions on the way clinicians and researchers measure arm and hand recovery and improvements after stroke.

You are invited to take part in this study.  Please read this Explanatory Statement in full before deciding whether or not to participate in this research.

 If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers by telephone (03 99030555) or email (Natasha.Lannin@Monash.edu)

**What does the research involve?**
The research study aims to identify appropriate outcome measures used with adults after stroke to determine how best to measure improvements in the hand and arm that are meaningful and acceptable to stroke survivors. We would like to gain your opinion on the use of outcome measures, in particular for research studies.

You have been invited because you have had a stroke or are a family member / caregiver of someone who has had a stroke.

If you decide to take part in the research project, you will complete a survey that will ask you questions about your experience with arm and hand tests, and what improvements you feel matter the most.

This will take approximately 10 minutes.

We will ask you questions about your stroke affected hand and arm and the recovery you have experienced as well as the types of outcome measures you have experienced. You will be able to click on links to see the types of tests and questions, and then you will be asked to share your thoughts on how often you may be willing to complete tests, as well as where you'd be willing to have the outcome measure completed.

The survey asks specifically about your opinions on the ways for measuring arm and hand recovery. You are not being asked to personally answer the assessment items on your arm and hand movement. The survey will also collect basic demographic information, such as when you had your stroke, your age, gender, and background. We will also ask you to give an indication of how well your hand and arm moves now.

**Consenting to participate in the project and withdrawing from the research**
Submission of the online survey is an indication of your consent. By clicking the ‘I agree to participate’ button you are providing your permission for the research team to collect and use information about you for the research study. Participation in the research is voluntary and you may decline to participate, or withdraw at any time before completion of the survey, without explanation or penalty, by closing your web browser. Because your response is anonymous, that is, we do not collect names, it will not be possible to withdraw your data once your response has been submitted as we will not know what survey was yours.

**Possible benefits and risks to participants**
We hope to use information we get from this research study to benefit others who have a stroke, by ensuring that researchers measure the outcomes that matter most to stroke survivors. You may also gain insight into your own thoughts about arm recovery, which may help you when considering making future rehabilitation decisions.

If you experience any feelings of discomfort or distress while completing the survey and you require support, you can stop participating at any time. You can also tell a member of the research team and they will provide you with assistance or alternatively you can speak to your GP about your feelings.

**Payment**
To recognise your contribution, should you choose to participate, the research team is offering participants the chance to win one $100 gift card for your participation in the survey. Entry into the prize draw is optional and voluntary. To protect your anonymity associated with your survey responses, you will be taken to a different survey page to enter your email address. Please note the opening date for entries is 1/01/2024, the closing date for entries is 01/05/2024. The prize will be drawn on 06/05/2024.

**Confidentiality**
Information collected in the survey will be non-identifiable, so your identity will be unknown. When we publish or report the data (such as presenting at a conference or in a medical journal), it will be only in a format that cannot identify you.

**Storage of data**
The researchers will store the data collected from you in the survey for a minimum of 5 years after the publication of the research results on secure Monash University servers accessible only to members of the research team (current and future).

**Results**
A summary of the results will be available after July 2024. Please email the researcher, Professor Natasha Lannin (Natasha.Lannin@monash.edu) if you would like to receive a copy.

**Complaints**
Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics Committee (MUHREC):

Executive Officer Monash University Human Research Ethics Committee (MUHREC)
Office of Research Ethics and Integrity
Room 116, Administration Building B (3D) 26 Sports Walk, Clayton Campus Monash University VIC 3800
Telephone 03 9905 2052
Email: muhrec@monash.edu

**Reminder:** clicking on the **‘I agree to participate’ button** indicates that you **consent** to participate in this research project