Exercising, Socialising and Thinking: an Environmental Enrichment Model (ESTEEM) After Stroke

Phase III (Effectiveness)

PARTICIPANT INFORMATION STATEMENT

(Carers)

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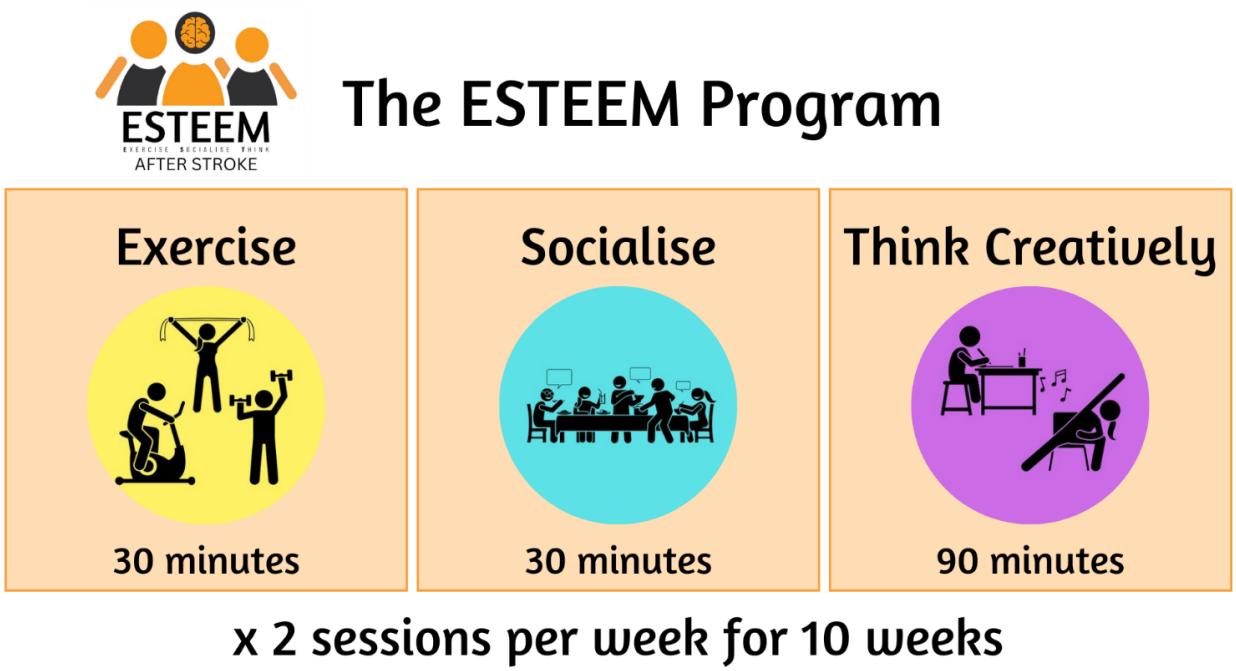

Introduction

You are invited to take part in **this research project** to help **researchers understand the benefits the ESTEEM Program for people who have had a stroke and their carers.**

Please **read this information carefully. Ask questions** about anything that you don't understand or want to know more about.

The Chief Investigator for this project is Dr Heidi Janssen.

What is the research about?

Researchers at the University of Newcastle have worked with stroke survivors, carers, health professionals and artists in the community to design the ESTEEM Program.

The ESTEEM Program is a community-based group program where people living with stroke come together twice a week to exercise, socialise and engage in arts-based activities such as visual arts and dancing. The ESTEEM Program is designed to provide further opportunities for rehabilitation in the community.

This part of the ESTEEM project which you are being invited to take part in, aims to determine if participating in the ESTEEM Program helps people recover after stroke.

Where is the research being done?

The study is a partnership project between **Hunter Medical Research Institute (HMRI), the University of Newcastle** and **Hunter New England Local Health District.**

Who can participate in the research?

People **aged 18 years or over** who are **providing care for someone who has previously had a stroke** and has **consented to participate in ESTEEM Phase III.**

For this project, a carer is defined using The Carers (Recognition) Act 2010 No 20, Section 5.

What choice do you have?

Participation in this study is **entirely voluntary**. You do not have to take part in it. If you do take part, you can **withdraw at any time** without having to give a reason. Whether or not you decide to take part your decision will not disadvantage you in any way.

What would you be asked to do if you agree to participate?

If you **agree** to participate in this study, you will be asked to **sign the Participant Consent Form.**

You will be asked to complete a series of **brief surveys** to understand your perceived quality of life and perception of your role as a carer 3 to 4 times over a 6-8 month period. The times when you will be asked to complete these surveys will align with the timepoints your family/friend with stroke will complete their surveys. Depending on their group allocation (Intervention (ESTEEM Now) or Control (ESTEEM Wait)), this data collection will occur:

(i) **Pre-waiting time** ESTEEM Wait group only (-10 weeks): at the start of the waiting phase

(ii) **Beginning:** at the start of the ESTEEM Program (0 weeks)

(iii) **End:** at the end of the ESTEEM Program (10 weeks), and

(iv) **Post:** 3 months after the end of the ESTEEM Program (20-24 weeks).

The surveys will be the same each time. At the first collection timepoint, we will collect additional information about yourself and your role as a carer. This and the other surveys will take approximately 15-20 minutes to complete and can be done online.

What are the risks and benefits of participating?

There are **no known risks** related to participation in this research project.

This research is unlikely to be of direct benefit to you. We hope this research project will improve the development and delivery of the ESTEEM Program to people who have had a stroke and may help other stroke survivors to reduce their risk of more strokes.

Will the study cost you anything?

You **will not be paid** for your participation in this study. Participation in this study can be done online.

How will your privacy be protected?

All the **information** collected from you for the study will be treated **confidentially**. To keep your records confidential, they will be identified by a code instead of your name, and all project records will be kept in a secure place to which no-one but the researchers have access.

Your personal information will be used and stored in accordance with Commonwealth Privacy Laws and the NSW Health Records and Information Privacy Act 2002. **All data will be held for a minimum of 7 years** and destroyed prior to disposal to ensure confidentiality is maintained.

The results of this study may be presented at conferences or in a scientific publication, but individual participants will not be identifiable in such presentations unless they provide written consent for this to occur.

If you decide to withdraw from the study the information you have contributed to the study already will still be used in the research as it cannot be separated from other participants' contributions. If you withdraw, we will not contact you for further information.

What do you need to do to take part?

Please read this Information Statement and be sure you understand its content before you consent to take part. If you would like to take part, please follow the instructions provided to **complete the consent form**. You may consent to this research by signing the attached form or over the phone with a member of the research team.

Further Information

You may wish to consult with your doctor, a relative or friend before agreeing to take part in this study. If you have **any questions** or would like further information concerning this project, you can contact **Dr Heidi Janssen** via phone 0473 434 389 or email Heidi.Janssen@health.nsw.gov.au.

This information statement is for you to keep.

Thank you for considering the invitation to take part.

Yours sincerely,

Dr Heidi Janssen

Principal Co-ordinating Investigator

Complaints about this research

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2023), produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

Should you have **concerns about your rights** as a participant in this research, or you have a **complaint** about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, please contact the HNE Research Office, Hunter New England Local Health District, Level 4 West, HMRI, Lot 1 Kookaburra Circuit, New Lambton Heights NSW 2305, telephone (02) 4921 4140, email HNELHD-ResearchOffice@health.nsw.gov.au and quote reference 2020/ETH01723.