The development of a telehealth exercise program for people who have had a stroke

INFORMATION FOR PARTICIPANTS

Introduction

You are invited to take part in a research study to develop an exercise program for people who have had a stroke that will be delivered via the internet. The exercise program will not be tested in this research project but plans are currently underway to test the program in the future. This research project is being conducted as a part of the requirements for a doctorate by research degree at the University of Newcastle. The PhD candidate is Emily Ramage, supervised by Associate Professor Coralie English (principal supervisor), Associate Professor Catherine Said, Dr Elizabeth Lynch and Dr Amanda Patterson.

What is the research about?

Becoming more physically active after stroke reduces the risk factors associated with having another stroke in the future. Researchers at the University of Newcastle are designing an exercise program for people who have had a stroke aimed at increasing their physical activity.

It can be challenging to get more active when living with the effects of stroke. Stroke survivors might be more physically active if health professionals supervise their exercises at home via the internet.

It is very important that this exercise package meets the needs of those who use it. This research project will involve people who have had a stroke, health professionals, researchers and other members of the community who are involved in the delivery of exercise services. Together they will use their knowledge and experience to design a program that everyone can and wants to use.

The exercise program developed through this research is planned to be tested in the near future by the research team involved in this project.

Where is the research being done?

The study is being conducted within The University of Newcastle, NSW and Western Health, VIC.

Who can participate in the research?

Participating in this research is suitable for you if you are an adult aged 18 years or over who can contribute knowledge and experience to support the development of an exercise program.
program for people who have had a stroke.

You will be selected by the researchers who are looking to include people with a broad range of experience. People chosen to participate in the workshops will represent a variety of stakeholders including researchers; clinicians; stroke survivors; carers; healthcare service managers; and relevant non-government organizations, e.g. ‘the Stroke Foundation’.

Those selected will be recruited in one of 5 ways:

1. The Hunter Stroke Research Volunteer Register
2. Websites or social media
3. Have previously participated in research through the University of Newcastle and provided consent to be contacted about future research
4. Identified by a health professional and provided consent to receive further information about the study
5. Identified by the research team using their professional networks and provided consent to receive further information about the study

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. Whatever your decision, please be assured that it will not affect your medical treatment or your relationship with the staff who are caring for you.

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 then be asked to attend one workshop at the University of Newcastle or an alternative location that is convenient for participants with other people with different knowledge and experience to contribute to support the development of the exercise program – we will be inviting stroke survivors including those who have experienced exercise programs delivered via the internet, stroke survivors who have chosen not to use internet delivered exercise, health professionals, health service managers and the Stoke Foundation. The workshops will be no longer than 2 hours in length.

During the workshop you will be presented with information regarding a proposed exercise intervention that is being developed to help people with stroke to increase their physical activity levels to reduce the risk of having another stroke. You will then be supported by a member of the research team to share your knowledge, experience and opinions regarding exercise. The discussion will focus on what you and other participants in the workshop believe will be important to the success of such a program.

Your experience and opinions will be used along with those of other participants to develop an exercise program designed for people who have had a stroke, delivered by health
professionals over the internet. Notes will be taken by the researchers throughout the workshop which will also be audio recorded.

You may be asked to complete a brief questionnaire at the beginning of the workshop you participate in. This will seek to collect demographic information which may include your age, your prior experience with exercise, and if applicable, the amount of time since your stroke and your current ability, or your experience with telehealth and any professional qualifications relevant to exercise prescription. This questionnaire and will take less than 5 minutes to complete.

All notes, questionnaires and audio recordings are confidential and will only be accessed by members of the research team.

**What are the risks and benefits of participating?**

**Risks**

There are no known risks related to participation in this research project. It may be inconvenient to travel to, and spend time at the workshops.

**Benefits**

This research is unlikely to be of direct benefit to you. We hope this research project will improve the development and delivery of exercise programs to people who have had a stroke in the future, 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. You will be required to cover your own travel expenses (parking will be provided) for study visits. There may be an option for you to access the workshops via videoconference over the internet if attendance at the workshop is not possible for you.

**How will your privacy be protected?**

All the information collected from you for the study will be treated confidentially, and only the researchers named above will have access to it. The study results 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.

Your personal information will be accessed, used and stored in accordance with Commonwealth Privacy Laws and the NSW Health Records and Information Privacy Act 2002.

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.
All data including questionnaires, audio recording and the notes from the workshops will be kept by the site at which the workshop occurred. During and after the project, data will be stored on a password-protected file or in a secure filing cabinet and accessed only by the researchers named on this document. All data will be held for a minimum of 7 years and destroyed prior to disposal to ensure confidentiality is maintained.

Further Information

When you have read this information, Emily Ramage or Associate Professor Coralie English will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact them [Emily Ramage m: 0408 669 204, e: emily.ramage@uon.edu.au or Coralie English ph: ph:02 4913 8102 e: coralie.english@newcastle.edu.au].

Researchers involved in this research project are:

Associate Professor Coralie English, Associate Professor, School of Health Sciences and Priority Research Centre for Stroke and Brain Injury, University of Newcastle, NSW

Associate Professor Catherine Said, Associate Professor Physiotherapy, Western Health, Furlong Rd, St Albans, VIC

Dr. Elizabeth Lynch, Research Fellow, Adelaide Nursing School, University of Adelaide, SA

Dr Amanda Patterson, Senior Lecturer, School of Health Sciences and Priority Research Centre for Stroke and Brain Injury, University of Newcastle, NSW

Dr Di Marsden, Conjoint Fellow, School of Medicine and Public Health, University of Newcastle, NSW

Dr Heidi Janssen, Conjoint Lecturer, School of Health Sciences, University of Newcastle, NSW

Margaret Galloway, PhD Candidate, School of Health Sciences, University of Newcastle, NSW

Meredith Burke, member of the Hunter Stroke Research Volunteer Register Steering Committee, University of Newcastle, NSW

Emily Ramage, PhD Candidate, School of Health Sciences, University of Newcastle, NSW

This information statement is for you to keep.

Thank you for considering the invitation to take part.

Yours sincerely,

Coralie English
Complaints about this research

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference: 18/12/12/4.05.

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, to Dr Nicole Gerrand, Manager, Research Ethics and Governance Office, Hunter New England Human Research Ethics Committee, Hunter New England Local Health District, Locked Bag 1, New Lambton NSW 2305, telephone (02) 49214950, email HNELHD-HREC@hnehealth.nsw.gov.au

AUTHOURISATION STATEMENTS
Generic (to be included on Master Versions of Information Statements for multicenter studies)

The conduct of this study at the University of Newcastle, Newcastle, NSW and Western Health, St Albans, VIC has been authorised by Hunter New England Local Health District. Any person with concerns or complaints about the conduct of this study may also contact Dr Nicole Gerrand, Manager Research Ethics & Governance Office on 4921 4950 and quote reference number SSA/18/HNE/319.