Designing a diet and physical activity web-based platform to reduce secondary stroke risk for stroke survivors: An integrated knowledge translation approach

INFORMATION FOR PARTICIPANTS/ CONSENT FORM

Introduction

You are invited to take part in a research study where you will help design a web-based platform for people who have had a stroke.

This platform will have information and tips from health professionals, stroke survivors and scientists about healthy eating and physical activity that can be done to reduce the risk of having another stroke.

This research project is being conducted as a part of a doctorate by research degree at the University of Newcastle. The PhD candidate is Dina Pogrebnoy, supervised by Professor Coralie English (principal supervisor), Dr Lesley McDonald-Wicks, Dr Amanda Patterson and Dr Amy Dennett.

What is the research about?

Eating nutritious food and increasing physical activity after stroke reduces the risk of having another stroke. But we know that the effects of a stroke can make it difficult to get more active and to change eating patterns.

Our research team, which includes stroke survivors, health professionals and scientists, designed the *i-REBOUND* program. This program aims to make it easier to eat healthy and move more.

This project is about making the *i-REBOUND* program available online so that people can access it when they need it, where they need it.

This platform needs to be user-friendly for people with a range of impacts from their stroke, including movement, thinking or memory, and speech. It is very important that it provides a good experience for people who use it.

Where is the research being done?

The study is being conducted by The University of Newcastle, NSW and Eastern Health, VIC. You can take part from your home or somewhere else where you can do zoom calls.

If you're not sure about using zoom, the research team can help you practice before the workshops, so that you feel comfortable on the day.

Who can participate?

People over 18 who can contribute knowledge and experience to support the development of the web-based platform, including:

- health professionals,
- stroke survivors,
- carers,
- healthcare service managers,
- and relevant non-government organizations, e.g. 'the Stroke Foundation'.

You are receiving this information because you are either,

1. are a member of the Stroke Research Register, Hunter, or
2. saw information on a website or on social media, or
3. previously took part in the codesign workshops for the physical activity or diet interventions as part of the University of Newcastle telehealth trial and gave consent to be contacted about future research
4. were told about this research by one of your health professionals and gave consent to have this sent to you
5. were identified by the research team using their professional networks and you gave consent to receive further information about the study

What Choice do you have?

Participation is entirely voluntary. You do not have to take part if you do not want to. 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 any current medical treatment (if applicable) or your relationship with the staff who are caring for you, or who you work with.

What will the study involve?

1. You will be asked to sign the Participant Consent Form.
2. Attend two workshops via videoconference (eg zoom) of no longer than 2 hours in length.

There will be people with a range of different knowledge and experience in the workshops with you.

Workshop 1 – Help design the prototype

Stroke survivors or carers will work with a member of the research team and **3 - 6 others** and discuss, from your personal experience:

- What might make it hard to engage with a web-based platform for healthy eating and physical activity.

- Which skills or tools people might need to make it easier for them to use the platform.

You will be shown the *i-REBOUND* diet and physical activity programs that have been designed for stroke survivors as part of our previous work in this large project. You will be asked your views on how they should be adapted for the online platform.

You will be asked to complete a brief questionnaire (5 minutes) at the beginning of each workshop to collect your age, your prior experience with web-based platform use, and if applicable, the amount of time since your stroke and your current ability, or any professional qualifications relevant to diet or physical activity interventions. Help to complete this questionnaire will be available if you need it.

Other stakeholders including researchers; clinicians; healthcare service managers; and relevant non-government organisations, e.g. 'the Stroke Foundation' will be included in a separate workshop to incorporate their views prior to developing the prototype of the web-based platform. The research team will then use information from both workshops to develop a prototype of the web-based platform.

These workshops will be recorded within zoom, and notes will be taken by researchers to capture all information provided.

Workshop 2 – Feedback on the prototype

Stroke survivors or carers will work with a member of the research team and **3 - 6 others** to share your feedback and opinions on any necessary modifications for improvements to the platform.

Other stakeholders including researchers; clinicians; healthcare service managers; and relevant non-government organisations, e.g. 'the Stroke Foundation' will be included in a separate workshop to incorporate their feedback and suggested modifications on the prototype of the web-based platform.

The research team will use information from both workshops to refine the prototype of the web-based platform.

All notes, questionnaires and meeting recordings are confidential, will be stored securely 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. All workshops will be run via an online meeting platform (eg. zoom), therefore there will be no travel inconvenience associated with participation.

Benefits

We hope this research project will help with the development of a diet and physical activity web-based platform for people who have had a stroke and may help stroke survivors reduce their risk of repeat strokes.

Will the study cost you anything?

There is no cost to participate, however, you will need to cover the cost of internet used for the workshops if you are at your home. You won't be paid to take part.

How will your privacy be protected?

The information collected from you will be treated confidentially, and only the researchers named on this project will have access to it. The study results may be presented at conferences or in scientific publications. 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, recordings from meetings and notes from the workshops will be kept on a secure server which is password protected. 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, Dina Pogrebnoy or Professor Coralie English will discuss it with you and answer any questions you may have. If you would like to know more at any stage, please feel free to contact them
Dina Pogrebnoy Mob: 0403432415, Email: dina.pogrebnoy@uon.edu.au or
Coralie English Ph: 02 4913 8102, Email: coralie.english@newcastle.edu.au .

Full list of researchers involved in this research project can be requested.

This information statement is for you to keep.

Thank you for considering the invitation to take part.

Yours sincerely,

Coralie English
Principal Coordinating Investigator
Associate Professor the University of Newcastle

Dina Pogrebnoy
Principal Investigator
PhD Candidate the University of Newcastle
0403432415

Complaints about this research

Ethics:
This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference 2021/ETH00360.

Governance:
The conduct of this research has been authorised by the Hunter New England Local Health District to be conducted at the Hunter New England Local Health District site.

Complaints about this research:
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 3, POD, HMRI, Lot 1 Kookaburra Circuit, New Lambton Heights NSW 2305. Telephone: 02 4921 4140. Email: HNELHD-ResearchOffice@health.nsw.gov.au and quote the reference number **2021/ETH00360**.

Consent Form

Declaration by Participant

I have read the Participant Information Statement, or someone has read it to me.

I understand the purposes, procedures and risks of the research described in the project and understand that workshop will be recorded within zoom.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.

I understand that I will be given a signed copy of this document to keep.

☐ I wish to be notified about results of this study. My contact details are below:

_____

☐ I wish to be notified about future research studies.

Name of Participant (please print)

Signature Date

Declaration by Researcher†

I have given a verbal explanation of the research project; its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher† (please print)

Signature Date

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine care or my relationships with the researchers.

Name of Participant (please print)

Signature Date

In the event that the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher†

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Researcher (please print)

Signature Date

† An appropriately qualified member of the research team must provide information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature