

Plain Language Statement

Medicine, Dentistry and Health Sciences
Department of Physiotherapy



Project: Co-design of a Personalised Physical Activity Intervention for Stroke Survivors

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Introduction

Thank you for your interest in this research project. The following pages will provide you with information about the project, so you can decide if you want to take part in this research.

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

Your participation is **voluntary**. If you don't want to take part, you don't have to. If you are participating, you can **withdraw** at any time.

What is this research about?

Physical activity is important for:

- improving function after stroke and
- for preventing future strokes.

Many people find it difficult to be active after having a stroke.

We need better programs that help stroke survivors to make regular physical activity a part of their everyday lives.

We will use an **integrated knowledge translation approach** to design physical activity programs. This means stroke survivors, carers, therapists, healthcare workers, researchers and others involved in stroke rehabilitation will work together on the project.

In this project we want to:

- develop personalised and engaging physical activity programs for stroke survivors.
- develop a process for stroke survivors, their carers and therapists to work together to create their personalised physical activity programs/plans
- evaluate how researchers and stroke survivors have worked together in this project
- we aim to “co-design” these programs with input from stroke survivors, their carers, and healthcare workers and therapists who work with stroke survivors.

It is important these programs:

- meets the needs of stroke survivors, carers and therapists,
- can support people to participate in safe and effective physical activity,
- is something that people will actually use.

Who can participate in this research?

We are inviting adults who have had a stroke, people who are carers for stroke survivors and health professionals and researchers who work with people recovering from stroke to participate in this study. All participants need to be able to participate in workshops or interviews described below.

What will I be asked to do?

If you agree to participate in this study, you will be asked to sign the Participant Consent Form, complete a questionnaire, and attend workshops and/or interviews as outlined below.

You will be asked to complete a brief questionnaire (either at the beginning of the workshop or before the workshop). The questionnaire will ask for information such as:

- age
- amount of time you have cared for someone who has had a stroke
- occupation (if applicable)
- experience with telehealth
- the stroke survivor’s physical ability and physical activity

The questionnaire will take less than 5 minutes to complete.

You will then be asked to join **1 or 2 workshops** that will run for no longer than **2 hours each**. The workshops will have between 2 and 8 participants each and will be held approximately 3 months apart. You can take part in the workshops either in person at the University of Melbourne or online via a video conference. The workshops may involve:

- people who have had a stroke,
- carers,

- health professionals,
- researchers,
- other members of the community involved in physical activity or rehabilitation after stroke.

The group will be supported to discuss their **knowledge, opinions and experiences** of helping someone with a stroke to participate in physical activity to help us create physical activity programs, resources and processes.

If the workshop is run online, you can join the video conference system for the workshop via an internet link or telephone call. There will be a chance to familiarise yourself with the video conferencing system before the workshop. This is likely to take a maximum of 15 minutes and is optional.

Regular breaks will be provided during the workshops. The workshops will be audio video recorded so that the researchers can review the information discussed. The researchers will also take notes during the workshop.

You will be provided with a summary of the discussion after each workshop. You will have the opportunity to give the researchers feedback if you think something is not clear or was missed.

Any reasonable parking and travel costs for attending the workshops will be reimbursed.

If you are unable to attend a workshop, you may be offered the opportunity to participate in a one-on-one interview to discuss your **knowledge, opinions and experiences** of helping someone with a stroke to participate in physical activity programs.

After each workshop or interview you will be asked to complete an online questionnaire evaluating the partnership between researchers and participants and your involvement in the project. You may also be asked to participate in a half-hour interview (via video conference or in person) about your involvement and the project. If you choose to participate in an interview, it would be audio video recorded.

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

What are the possible benefits?

This research is unlikely to be of direct benefit to you. We hope this research will help improve the amount of physical activity undertaken by people with stroke by developing processes to create programs that are personalised and engaging. You will not be paid for your participation in this study.

What are the possible risks?

We understand when participating in this research there is a chance that you may become upset while remembering or talking about your experiences. Our experienced researcher team will provide you with support if this occurs. If you **do not want** to talk about a topic you do not have to. You can **leave the workshop immediately** if you wish.

If you feel distressed as a result of the study you will be encouraged to contact:

- the Principal Investigator,
- Your GP,
- AND/OR
- Beyond Blue (available 24 hours a day) on 1300 224 636.
- Mental Health Line on 1800 011 511

You can **withdraw** from the study at any point if you feel distressed.

Do I have to take part?

No. Participation is completely voluntary. You are able to withdraw at any time. If you choose to withdraw, any information you have previously shared will **be included** in the results as we cannot separate it from other participants' discussions in the workshop. If you withdraw we will not ask you for any follow-up data. Your decision to participate will not impact on your care in any way.

Will I hear about the results of this project?

All participants will be provided with a summary of the project. You can also have a copy of the resources developed.

The study results may be presented at conferences or in a scientific publication. In any publication or presentation information will be presented so that **you cannot be identified**.

What will happen to information about me?

All the information collected from you for the study will be treated confidentially. Only the researchers named above will have access to it.

Your personal information will be accessed, used and stored in accordance with Commonwealth Privacy Laws. All data including questionnaires, audio video recordings and the notes from the workshops will be kept by the University of Melbourne. Data will be stored on a password-protected file or in a secure filing cabinet. It will only be accessed by the researchers named on this document.

All data will be held for 5 years after the last report is published. After this time, the data will be destroyed to ensure confidentiality is maintained. You have the right to access information about you collected and stored by the researchers. Please contact one of the researchers named below if you would like to access your information.

Who is funding this project?

This project has been funded by the University of Melbourne Early Career Researcher Grant Scheme (\$36,000).

Where can I get further information?

If you would like more information about the project, please contact the Responsible Researcher: Dr. Natalie Fini.

Tel: 0401 303 749 or Email: natalie.fini@unimelb.edu.au

Who can I contact if I have any concerns about the project?

If you have any concerns about the project, you can contact the Responsible Researcher: Dr. Natalie Fini.

Tel: 0401 303 749 or Email: natalie.fini@unimelb.edu.au

Alternatively, this research project has been approved by the Human Research Ethics Committee of The University of Melbourne. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Manager, Human Research Ethics, Research Ethics and Integrity, University of Melbourne, VIC 3010.

Tel: +61 3 8344 2073 or Email: HumanEthics-complaints@unimelb.edu.au.

All complaints will be treated confidentially. In any correspondence please provide the:

- name of the research team,
- OR the name of the research project,
- OR the ethics ID number of the research project: 2021-21050-18630.