Participant Information Sheet

Study title:	Acceptability and usability testing of a co-designed educational resource for family members supporting stroke survivors to participate in physical activity.	
Principal investigator:	**Name:** Dr Ally Calder **Department:** School of Physiotherapy **Position:** Lecturer	Contact phone number: 027 445 0415 (feel free to text or call) (03) 244 1030

Introduction

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the aim of this research project?

Physical activity (PA) improves stroke survivors' function and healthy well-being. Despite these benefits, stroke survivors demonstrate very low levels of PA compared to the general population because they face personal and environmental barriers. Many stroke survivors rely on family members (i.e., spouse/partner, children) for physical, cognitive, emotional, and social support. However, families and stroke survivors feel vulnerable when transitioning from inpatient rehabilitation to the community because they have less access to health professional support. While clinical stroke guidelines recommend health professionals actively educate stroke survivors and their family in secondary prevention (e.g., participation in PA) after discharge, families report they receive very little explicit information about why, how, or where to be physically active. To address these gaps, the Principal Investigator Dr Ally Calder co-designed an educational resource in collaboration with a small group of female partners of male stroke survivors in a previous study. The aim of the

resource was to educate, guide, and empower partners to support male stroke survivors PA participation.

The purpose of this current study is to explore family members of stroke survivors' perspectives on the usability and acceptability of the educational resource co-designed in Dr Calder's previous research. At the completion of the research the educational resource will be reviewed and refined with a wider audience of families with the lived experience of stroke. The final product will provide helpful information for families supporting stroke survivors to participate in physical activity. Co-created resources are more likely to be effective because they may empower families to feel confident in their support role. If families feel in control and able to cope, it is likely that the stroke survivors' participation and subsequent health outcomes will be enhanced.

Who is funding this project?

This research project has been awarded funding from the Neurology Special Interest Group (NSIG) of Physiotherapy New Zealand (PNZ).

Who are we seeking to participate in the project?

We are seeking 10-15 families of community dwelling stroke survivors, who are at least 6 months post stroke to participate in this study. Acknowledging that stroke affects the entire family, all adult family members (≥18 years) along with their adult stroke survivor are eligible to participate in this research study.

Cultural safety and responsiveness for Māori and Pacific whānau with the lived experience of stroke: If you identify as Māori of Pacific whānau of a stroke survivor, we wish to acknowledge that the original educational resource was developed primarily from a Pākehā perspective. We recognise therefore that the original educational resource may not be acceptable, meaningful, or culturally relevant for people whose cultural identity or worldview differs from a Pākehā perspective. Therefore, we wish to offer Māori and Pacific whānau a choice for participation in this research study. Māori and Pacific whānau are very welcome to participate in this current study if they wish to do so, or they may choose to participate in a future separate study (under development). These future studies will begin from an open, undetermined place, enabling storytelling, korero, and talanoa to prioritise the voices specifically of Māori or Pacific whānau.

If you participate, what will you be asked to do?

The research involves three phases.

Phase 1: You will be invited to complete a brief demographic questionnaire which will include your age, gender, ethnicity, time post stroke, relationship to stroke survivor (i.e., partner, spouse, child, grandchild), and level of education. Each participating family will also be provided with the educational resource (1-2 copies per family) in an electronic or hard copy format according to your preference. The educational resource will include prompts to guide your perspectives about the presentation of the information (e.g., attractiveness, colour, font, spacing), the written content (e.g., accuracy, completeness, language, understandability, cultural relevance), and the acceptability of

the imagery. We will also ask you to identify any missing aspects and provide ideas for modifications for the educational resource to enhance the meaningfulness and cultural relevance.

You may provide written, or audio recorded comments and you will have approximately four-weeks to complete the activity. We anticipate it may take between 1-2 hours to provide comments. The research team will provide weekly contact (via telephone or email) as reminders and for troubleshooting. On completion of the activity, you will return your educational resource comments, completed consent forms, and demographic questionnaires to the researchers (electronically or in hard copy). If you chose to receive the documents as hard copies will be provided with stamped addressed envelopes to return the completed documents. The research team will summarise your perspectives and return these to you for additional comments.

Phase 2: We will invite your family to participate in an interview. This will allow us to understand and elaborate on your perspectives to ensure we have captured your thoughts accurately. The topics discussed at the interview will be informed by your comments in Phase 1. In general, we will explore 1) the meanings behind your perspectives you provided in Phase 1, 2) the acceptability of the resource for other families of stroke survivors, and 3) dissemination formats that would be useful, meaningful, and relevant.

The interviews will be conducted by two members of the research team in-person, by telephone, or Zoom depending on your preference and last approximately 30-60minutes. One researcher will facilitate the interview, while the second researcher will take field notes. Interviews will be audio recorded and transcribed verbatim. Interviews conducted electronically will be transcribed using the Zoom auto-transcribe function and in-person interviews will be transcribed by a paid transcriber. A summary of the results will be provided and you will be welcome to provide additional comments if you wish.

Phase 3: The research team will modify the educational resource according to the participants perspectives. You will be provided with the next version (version 2) of the educational resource to provide further comments. We anticipate the time required for participants to review and provide feedback for version 2 of the educational resource will be approximately 30-60 minutes. The research team will make further refinements and create version 3. You will be provided with version 3 at the end of the study.

Each family will be offered a $50 supermarket voucher as a token thank you for your participation.

Is there any risk of discomfort or harm from participation?

There is no anticipated risk of physical or psychological harm from participation in this study. Should you feel uncomfortable with the content, discussion, or direction of the interviews, you may decline to answer questions. If you feel distressed for any reason, the researchers will stop the interview and provide support while you recover. Once you have recovered, if you wish, we will continue with the interview, or we will offer to continue the interview at a different time, or you may choose to withdraw from the study at any time without having to provide a reason for doing so.

What data or information will be collected, how will they be used, and what about anonymity and confidentiality?

Your demographic information and signed consent forms will be collected as an electronic or hard copy. Hard copies will be scanned. All demographic information will be kept on the Principal Investigator's University of Otago password protected computer for 10 years. The hard copies will be destroyed. Any personal information (such as contact details) will be destroyed at the completion of the project even though the data derived from the research will, in most cases, be kept for much longer or possibly indefinitely.

At the beginning of the interview, the researchers will ask for your consent to audio-record the interview. The interviews will be audio-recorded and stored on the researchers' password protected computer. They will be transcribed word for word, checked for accuracy and de-identified to protect your anonymity. Once this process has occurred, the audio-recordings will be permanently deleted from the computer. The de-identified transcripts will be kept for 10 years on the researchers' password protected computer. During the interview one researcher will take notes which will be key points that you raise. These notes will not contain your name in order to protect your privacy. Only the named researchers and the paid transcriber will have access to your interview data.

The research team will be writing the results of the project and will present the findings to health professional colleagues at conferences, disability organisations, and submit a manuscript to a peer-reviewed academic journal article. The final educational resource will be freely available to all participants.

You will not be identified personally in any report of this study. We will use our best efforts to preserve anonymity of you in these reports.

If you agree to participate, can you withdraw later?

You may withdraw from participation in the project before its completion (May 2025) without having to provide a reason for doing so.

Any questions?

If you have any questions now or in the future, please feel free to contact:

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This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email humanethics@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.