Appendix B - Participant Information Sheet

**Date Information Sheet Produced:**

2 March 2022

**Project Title**

Facilitators and barriers to adherence to a physical activity for people with Multiple Sclerosis (MS) in New Zealand: A narrative inquiry.

**An Invitation**

Kia Ora. My name is Debbie Skilton, and I am a post graduate Sport & Exercise student working towards my MPhil in Sport & Exercise. I’d like to invite you to participate in a narrative study to explore the experience of physical activity from your point of view, as a person living with Multiple Sclerosis, within the environment that you live. I would like to gather a rich personal experience of MS and discover and analyse your experience of physical activity, in what ways you keep active and why. The research will be proactive in nature and capture information about positive habits.

Your participation in this project is entirely voluntary (your choice). You can withdraw at any time.

**What is the purpose of this research?**

The purpose of this research is to identify the barriers and facilitators to physical activity from the perspective of people with MS in New Zealand, with a view to identifying the motivations and experiences of those people diagnosed with MS who are currently physically active. The information gained will guide clinicians and exercise professionals to design prescribe, promote, and deliver physical activity programmes and support services that meet the needs and challenges of those with MS and to maximise their health outcomes.

The findings of this research may be used for academic publications and presentations.

**How was I identified and why am I being invited to participate in this research?**

You will have been involved in previous studies through the Health & Rehabilitation Research Institute (HRRI) and consented to be contacted for further related research or you would have seen advertising either physically or online and contacted the researcher involved in this study.

You are eligible for this study if you meet the following criteria:

* You were diagnosed with MS more than 3 months ago
* Your MS is currently stable, and your symptoms are controlled
* You are physically active. The level of physical activity needed to participate is all activities beyond that which would be considered sedentary or rest. This encompasses completion of household chores, engaging in participatory activities with others and includes modes of self-transportation like walking and wheeling.
* You are not an elite athlete
* You are not undertaking any structured rehabilitation programmes
* You do not have any cognitive or communication difficulties that prevent you from taking part and you are also able to participate and communicate in the English language.

**How do I agree to participate in this research?**

You can contact us on the details below if you wish to take part in the study. You will need to undergo a brief screening assessment over the telephone for us to determine whether you are eligible to participate. Prior to taking part, you will need to complete a consent form. You will have time to consider if you wish to take part in this study and ask any questions before providing consent to take part.  A consent form is attached to this information sheet.

Your participation in this research is voluntary (it is your choice) and whether you choose to participate will neither advantage nor disadvantage you. You can withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

**What will happen in this research?**

The project involves participation in a one-on-one interview about your experience with physical activity. The interview will occur either in person or online via a digital platform. If you choose to take part, the interview will take approximately 1 hour. The interview will be audio-taped, and notes will be taken during your interview.

**What are the discomforts and risks?**

The research concentrates on proactive actions and positive physical activity habits so there will not be any discomfort or risk in sharing your experiences.

You may find the interview uncomfortable at times, particularly if your experience with physical activity has not always been a positive one. However, it is important to us that you are honest about your experiences.

**How will these discomforts and risks be alleviated?**

You can choose not to talk in depth about negative experiences if they cause you distress, but we do ask you to be open about your experience of physical activity and to give suggestions about improvements and support requirements. AUT Health Counselling and Wellbeing is able to offer three free sessions of confidential counselling support for adult participants within the Auckland area in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research and are not for other general counselling needs. To access these services, you will need to:

* + drop into our centres at WB219 or AS104 or phone 921 9992 City Campus or 921 9998 North Shore campus to make an appointment. Appointments for South Campus can be made by calling 921 9992
  + let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this Information Sheet

Alternatively, the research team can assist you finding appropriate support through your own General Practitioner.

You can find out more information about AUT counsellors and counselling on <http://www.aut.ac.nz/being-a-student/current-postgraduates/your-health-and-wellbeing/counselling>.

**What are the benefits?**

While there are no immediate benefits to you personally for taking part in this study, you will be sharing your experience and thereby contributing to information that could provide better experiences for others with respect to physical activity.

It will help my peers in that it will provide rich contextual background to understand and identifying the motivations and experiences of those people diagnosed with MS who are currently physically active.

The information obtained will help exercise specialists to design, prescribe, promote, and deliver tailored physical activity programmes that meet the needs and challenges of those with MS and to maximise their health outcomes.

The study will help me as it will help me obtain my qualification.

**How will my privacy be protected?**

Interviews and recordings (and any notes taken) will be de-identified and confidential, will only be available to the research team. This de-identified data will be held on AUT premises for a period of 6 years, after which time it will be destroyed.

**What are the costs of participating in this research?**

The only cost to you is your time, which will be approximately 1 hour of interviewing with a researcher. The researcher will meet you at an AUT campus or and AUT affiliated location that is private and convenient to you or online using a digital platform. If there are any travel costs, then these will be reimbursed.

**What opportunity do I have to consider this invitation?**

We would like to know whether you wish to take part within 14 days of receiving this information sheet.

**Will I receive feedback on the results of this research?**

You can choose to receive a summary of the findings of this research, and you will have an opportunity to view and correct any transcript. You will get the summary when the study is completed, and the transcript will be discussed with you once it is fully transcribed.

**What do I do if I have concerns about this research?**

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Gemma Alder,[*gemma.alder@aut.ac.nz*](mailto:gemma.alder@aut.ac.nz)*,* (+649) 921 9999 ext 7815

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, *ethics@aut.ac.nz* , (+649) 921 9999 ext 6038.

**Whom do I contact for further information about this research?**

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

***Researcher Contact Details:***

Debbie Skilton, [debbie.skilton@aut.ac.nz](mailto:debbie.skilton@aut.ac.nz)

***Project Supervisor Contact Details:***

Gemma Alder, [gemma.alder@aut.ac.nz](mailto:gemma.alder@aut.ac.nz) 09 921 9999 ext 7815

**Approved by the Auckland University of Technology Ethics Committee on 9 June 2022, AUTEC Reference number 22/101.**