



Participant Information Sheet

Project Title: *Exercise 4 Endo*

Project Summary:

You are invited to participate in a research study being conducted by Dr. Cristy Brooks and Dr. Mike Armour from Western Sydney University, and Dr. Alex Semprini, Melissa Black, Allie Eathorne and Michaela Walton from the Medical Research Institute of New Zealand. The research seeks to understand the perceptions and experiences of exercise among women who have been diagnosed with Endometriosis.

How is the study being paid for?

No funding was received for this study.

What will I be asked to do?

For this research you will be asked to complete a survey about your feelings and experiences of endometriosis and exercise. You will be provided with a survey which will ask you for some demographic information, and then proceed with questions about the type of exercise you do, the symptoms you experience and how you treat them, and how effective exercise is in terms of managing symptoms you may experience. We will also ask you what reasons you may have for exercising or not exercising and whether you may consider exercise as a way to manage your symptoms in the future.

How much of my time will I need to give?

The time this survey takes to complete will vary between participants depending on how much (or little) detail they provide. We estimate this will take approximately 20 minutes.

What benefits will I, and/or the broader community, receive for participating?

Your participation will be a valuable addition to this research, and the study will contribute to a greater understanding of what type, duration and frequency of exercise woman with endometriosis do on a regular basis, as well as how it affects their endometriosis-related symptoms. This work will help us to understand how women with endometriosis view exercise and determine what we still need to understand. This will help us to provide a rationale for

more research into this area in the future, generate greater awareness of endometriosis and possible self-management tools for the ongoing symptoms of endometriosis, and possibly develop exercise-related guidelines for health practitioners to support and treat endometriosis sufferers more effectively. There are no immediate and direct individual benefits.

Will the study involve any risk or discomfort for me? If so, what will be done to rectify it?

It is possible that some of the themes that may arise with regards to endometriosis and exercise could involve recalling difficult circumstances or events which could lead to some psychological discomfort due to its possibly significant negative impact on women's lives. Your participation is voluntary and that you may withdraw from the research at any time. Should you find any of the topics distressing and would like to speak with a professional, there is a list of counselling services on: www.australiacounselling.com.au

Additional resources can be found at: www.endometriosisaustralia.org; <http://nzendo.org.nz>

If you experience significant distress, you are encouraged to reach out to Lifeline, a national crisis support charity. www.lifeline.org.au; www.lifeline.org.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050

Fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@advocacy.org.nz

Website: <https://www.advocacy.org.nz/>

How do you intend to publish or disseminate the results?

The results of the survey will inform future research on exercise for endometriosis sufferers, and will be published in a peer-reviewed journal article.

Will the data and information that I have provided be disposed of?

We will use your responses for the purposes of this research but please be assured that only the researchers will have access to the raw unidentifiable data you provide. However, your data may be used in other related projects for an extended period of time, and will be stored securely in accordance with Western Sydney University's Research Data Management Policy.

Please note that minimum retention period for data collection is five years post publication. The data and information you have provided will be destroyed after this 5-year period.

Can I withdraw from the study?

Participation is entirely voluntary and you are not obliged to be involved. If you do participate you can withdraw at any time without giving a reason. If you do choose to withdraw, any information that you have supplied will not be included in the final dataset, and will be securely disposed of. As responses will be anonymous, you will not be able to withdraw consent after the survey has been submitted.

Can I tell other people about the study?

Yes, you can tell other people about the study by providing them with a link to this survey, or Dr. Cristy Brooks' contact details. They can use these details to contact Dr. Brooks to discuss their participation.

What if I require further information?

Please contact Dr. Cristy Brooks, should you wish to discuss the research further before deciding whether or not to participate.

Dr. Cristy Brooks, Chief Investigator. Email: c.brooks@westernsydney.edu.au

What if I have a complaint?

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through Research Engagement, Development and Innovation (REDI) on Tel +61 2 4736 0229 or email humanethics@westernsydney.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you may be asked to sign the Participant Consent Form. The information sheet is for you to keep and the consent form is retained by the researcher/s.

This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is H15028.