



Participant Information Sheet

Project Title: The effectiveness and cost of Endometriosis self-care in Australian women: A nationwide survey

Project Summary:

You are invited to participate in a research study being conducted by Dr Mike Armour, Mr Justin Sinclair, Professor Caroline Smith from NICM, and Ms Jane Chalmers from the department of Physiotherapy, all from Western Sydney University. The research involves an online survey of women with endometriosis.

How is the study being paid for?

This study is internally funded by Western Sydney University.

What will I be asked to do?

You will be asked to fill in an online survey hosted by Qualtrics. To be eligible to participate in this survey you need to have either a confirmed diagnosis of endometriosis through a laparoscopy. The survey will ask about your background and your use (or lack of use) of self-care practices in the management of your endometriosis. Self-care can include breathing exercises, meditation, exercise, yoga, herbal therapies, cannabis or alcohol usage. The survey will ask you questions about your perception of the effectiveness of these self-care techniques, any negative effects from using these and how much money you have spent on these.

How much of my time will I need to give?

The survey will take approximately 15-30 minutes of your time. However, this time will vary depending on how many self-care techniques you have used. You will be required to complete the survey in one sitting as we do not collect your IP or use cookies, to protect your privacy.

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

At this stage there may not be any direct benefits for participating however the information this survey provides will be able to identify self-care techniques that women with endometriosis are currently using. This information may be used to direct future research to help improve health outcomes for women with endometriosis.

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

We do not foresee any risk to you from participating in this study; however, some of the questions are personal in nature and relate to menstruation and sexual intercourse. There are questions around cannabis or cannabis product usage which is currently illegal in Australia. If you do not wish to answer any specific question due to discomfort or personal preference, you can simply leave it blank or skip it. If this survey has raised questions or concerns about your pelvic pain there are helpful resources provided by the Pelvic Pain Foundation of Australia at <http://www.pelvicpain.org.au/information> and a list of support groups provided by Endometriosis Australia at <http://www.endometriosisaustralia.org/support-groups>. If you wish to speak to a counsellor regarding your experiences there is a list of counselling services on <https://www.australiacounselling.com.au/>

All answers to the survey are completely anonymous and no identifying data collected. Additionally, the survey does not log your location or IP address.

How do you intend to publish or disseminate the results?

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that the participant cannot be identified, via summaries of what we found, rather than individual data.

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

We will use your survey answers for the purposes of this research but please be assured that only the researchers will have access to the raw data you provide, these data are kept confidential, and that your data will not be used in any other projects. Please note that minimum retention period for data collection is five years post publication. The data and information you have provided will be securely disposed of.

Can I withdraw from the study?

Participation is entirely voluntary and you are not obliged to be involved. If you do participate you can stop filling in the survey at any time. Once you have submitted your answers we cannot remove them as we have no way of identifying your answers due to the anonymous nature of the survey. Whatever your decision, it will not affect your medical treatment or your relationship to anyone involved in this study.

Can I tell other people about the study?

Yes, you can tell other people about the study by providing them with Dr Armour's details or the Qualtrics link. If they would like more information they can then contact Dr Armour to discuss their participation in the research project and obtain a copy of the information sheet.

What if I require further information?

Please contact Dr Mike Armour should you wish to discuss the research further before deciding whether or not to participate

Dr Mike Armour, Chief Investigator, email m.armour@westernsydney.edu.au mobile 0415363201

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 H12394