



PARTICIPANT INFORMATION SHEET

PROJECT TITLE

The cost and impact of chronic pelvic pain in Australia: Focus groups

PROJECT SUMMARY

You are invited to participate in a research study being conducted by Dr Mike Armour, Professor Caroline Smith from NICM, Western Sydney University, Mrs Jane Chalmers and Dr Sowbhagya Micheal from Western Sydney University and Associate Professor Jason Abbott from UNSW. The research involves focus groups of women with chronic pelvic pain to explore their personal experiences of living with chronic pelvic pain.

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 attend a focus group in Sydney with eight to nine other women with chronic pelvic pain. There will be an experienced focus group facilitator present, and Dr Armour will also take notes and observe the focus group. You will be asked questions about your experiences with chronic pelvic pain. The topics discussed will be guided by the group on the day but will cover the experience you have had in the following areas: the diagnosis of your pelvic pain, the symptoms you experience, the impact your pelvic pain may have had on your social life, sports/leisure activities and romantic/sexual relationships, the impact your pelvic pain may have had on your education or work life, and what treatments (conventional or complementary) or lifestyle changes that you have found worked, or did not work, for your pelvic pain.

The facilitator will ensure you have a chance to give your opinion on each topic raised during the discussion however you do not need to participate on every question if you do not wish. The audio from this focus group will be recorded digitally and a written copy will be sent to you after transcription so you can check it and make sure you're happy that it is an accurate record of what you said. We will also collect some information from you about your age, employment status, and other demographic details, on a questionnaire which we will ask you to complete when you attend the focus group.

HOW MUCH OF MY TIME WILL I NEED TO GIVE?

The focus groups will take 90-100 minutes. To compensate you for your time, we are offering you a \$20 Red Essentials (Woolworths, Caltex and Big W) gift voucher once you have attended the focus group.

WHAT BENEFITS WILL I, AND/OR THE BROADER COMMUNITY, RECEIVE FOR PARTICIPATING?

You may benefit from the chance to interact and share common experiences with other women living with chronic pelvic pain. More broadly, your experiences and views will contribute a better understanding of the experience of chronic pelvic pain for women living in Australia. This increased understanding will identify any areas of unmet need that women with pelvic pain are experiencing in their healthcare.

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. There may be some distress or discomfort discussing personal issues where pelvic pain has had a negative impact on your life, or unpleasant/uncomfortable experiences with other people including romantic partners, friends or health care providers. We also recognise that some people feel uncomfortable when talking about matters relating to menstruation and sex. Our facilitators are experienced in conducting focus groups on health issues, and will ensure that you feel safe and respected during the focus group. During the focus group itself you will be able to take a break and leave the room if you find the topic distressing. Should you find discussion about any of the topics in the focus group distressing and would like to speak with a professional there is a list of counselling services on <https://www.australiacounselling.com.au>. There is also a list of support groups provided by Endometriosis Australia at <http://www.endometriosisaustralia.org/support-groups>.

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, except with your permission. All participants will be referred to by a pseudonym and no identifying details will be provided.

WILL THE DATA AND INFORMATION THAT I HAVE PROVIDED BE DISPOSED OF?

We will use your personal history and transcripts from focus groups 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 withdraw at any time without giving reason. 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. 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 H12019.