



Participant Information Sheet – General (Extended)

Project Title: Cannabis and Endometriosis during the COVID-19 pandemic

Project Summary:

You are invited to participate in a research study being conducted by Dr Mike Armour, Mr Justin Sinclair (PhD Candidate) and Mr David Varjabedian from NICM Health Research Institute, Western Sydney University, Australia, Dr Jane Girling, Dr Geoff Noller and Ms Maria Larcombe from Otago University, New Zealand, Professor Jason Abbott from University of New South Wales, Australia and Dr Mathew Leonardi from McMaster University, Hamilton, Canada.

Our teams recent research has found that people with endometriosis who live in Australia or New Zealand report using cannabis to help manage their endometriosis symptoms and reduce their endometriosis-related medication. The recent COVID-19 pandemic has limited health care access in many areas of the world; surgery has been delayed or cancelled in many locations, and normal medical care may be harder to access during this time. In contrast, in some locations cannabis dispensaries have been considered essential services and have been allowed to stay open.

We are interested in finding out if the COVID-19 pandemic and the resulting changes in access to normal medical care has caused a change in the usage of cannabis (or cannabinoid-containing products such as edibles) amongst people with endometriosis; this may be starting using cannabis, or if you are an existing cannabis user changing some of your usage habits such as using more cannabis or switching from one mode of administration (such as vaping) to another.

This information will help us better understand the role that cannabis plays in the management of endometriosis symptoms. **You do not need to be a current, or previous user of cannabis to participate.** It's important for us to have people who don't use cannabis also answer so we can see if there are differences in those that do or don't use cannabis.

How is the study being paid for? No external funding was received for this study.

What will I be asked to do?

This survey is open to people worldwide.

To participate in this survey you need to:

- Have been told by your doctor you have endometriosis.
- Be aged between 18-55

You will be asked to fill in an online survey hosted by Qualtrics. You will ask about your background (such as your age, which country you live in), how your endometriosis was diagnosed, what symptoms you have and how you manage these. If you are a current user of cannabis then questions about cannabis usage will be different depending on if you were using prior to COVID-19 or have started more recently but will cover how much you use, how you consume it (e.g. oil, vaporiser), if you've changed your usage recently, any side-effects you have had, and what endometriosis symptoms you are trying to treat.

How much of my time will I need to give?

Participation in the study will involve completing an online survey that will take 15-30 minutes. You will be required to complete the survey in one sitting as we do not collect your IP address or use cookies, to protect your privacy as you may be disclosing illegal activity if you are using cannabis when it is not legal in your area.

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 help inform what role cannabis might play in people with endometriosis. 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, and your answers are completely anonymous. We do not use cookies or collect your IP address. We also do not collect any identifiable information from the demographic questionnaire nor the quality of life survey, namely the EQ5D. We also recognise that some people feel uncomfortable when talking about matters relating to endometriosis and pelvic pain. Depending on your location please contact your local support and advocacy group if you need support or more information (<https://endometriosis.org/support/world-endometriosis-organisations-weo/>)

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?

Please be assured that only the researchers will have access to the raw data you provide. However, your data may be used in other related projects for an extended period of time, such as helping inform clinical trial design for potential trials on cannabis for endometriosis or pelvic pain.

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 the Qualtrics link. If they would like more information they can then contact Dr Armour to discuss their participation in the research project.

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

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.

This study has been approved by the Western Sydney University Human Research Ethics Committee. The Approval number is H13823.