WESTERN SYDNEY
UNIVERSITY

Participant Information Sheet – Movement Matters study

Project Title: Testing an online education resource for young people about movement for menstrual health conditions

Project Summary:

You are invited to participate in a research study being conducted by Dr Kylie A Steel, A/Prof Mike Armour, Dr Cristy Brooks, A/Prof Tanya Perich, Dr Emily Yang, A/Prof Carolyn Ee, and Vibhuti Rao from Western Sydney University, Melissa Perry from MRINZ, and Dr Millie Mardon and Georgia Gosse of Adelaide University. The research is looking to test an online education resource to teach young people about movement and exercise for menstrual health conditions.

If you are aged 16 years and older, live in Australia and have a menstrual health condition, you may be eligible to participate in the study. To confirm your eligibility, we will need to ask you more questions before you start.

How is the study being paid for?

The project is funded by a Western Sydney University seed grant.

What will I be asked to do?

You will be asked to participate in a study to help determine if an online web resource about movement and exercise for menstrual health conditions is acceptable for use by young people. To register your interest in participating, you will need to complete a short, online form to provide some basic information about you to help us figure out if you are potentially eligible. If you are potentially eligible, you will be asked to book in a time to speak to a member of the research team who will explain the study and get consent.

After initial assessment and consent you will be enrolled into the study. If you are under the age of 18 a parent or guardian will also need to consent for you to participate in the study.

Throughout the study you will have access to the online resource for one months (4 weeks). You can access and use the online resource as much as you would like during this time. The research team will send you reminders once during month via email about using the online resource. After using the resource for one month, you will be asked to complete some questionnaires about how you are feeling, how much movement and exercise you did, and how you think the study went.

If deemed acceptable, everyone will get free access to the new online education resource at the end of the trial.

How much of my time will I need to give?

We anticipate that accessing the online resource will take about one hour of your time. Completing the questionnaires will take around another 1 hour of your time. In total, we

Western Sydney University
ABN 53 014 069 881 CRICOS Provider No: 00917K
Locked Bag 1797 Penrith NSW 2751 Australia
westernsydney.edu.au

anticipate that you will give around 2 hours of your time to the project.

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

If you are currently suffering from a menstrual health condition, you may learn more about your condition and experience an improvement to your symptoms, although there is no guarantee that this will happen. You will also receive a $30 gift card for completing the study.

If the new online resource is found to be acceptable, it may have the potential benefit to help the wider community learn more about movement and exercise for menstrual health conditions.

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

We do not anticipate much risk or discomfort for participating in this study. You may experience some discomfort learning about menstrual health conditions. The research team will monitor you throughout the study. If you do report any side effects during the study, we will check in on you via email or telephone. It is important that if you have any side effects that you are concerned about at any time to contact the research team. If you think they are mild please contact the study staff via the contact details at the end of this sheet. If you feel they are serious or life threatening, please immediately seek medical attention from your GP or emergency department.

If you do experience any discomfort or distress relating to your menstrual and/or pelvic health condition, please speak to your GP or healthcare provider.

You may also access these resources:

- Beyond Blue https://www.beyondblue.org.au/
- Lifeline https://www.lifeline.org.au/
- Mindspot https://www.mindspot.org.au/
- Pelvic Pain Foundation of Australia https://www.pelvicpain.org.au/
- Jean Hailes for Women's Health https://www.jeanhailes.org.au/

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. No personal identifiers (e.g., names) will be published. Everyone will be assigned a pseudonym that will be used in the publications instead.

If you would like to receive a summary of research results individually, please tick the box on the online questionnaire.

Western Sydney University
ABN 53 014 069 881 CRICOS Provider No: 00917K
Locked Bag 1797 Penrith NSW 2751 Australia
westernsydney.edu.au

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. In accordance with the Australian privacy and other relevant laws, you have the right to request access to your information that we have collected and stored by the research team. Please contact the chief investigator, Dr Kylie Steel (k.steel@westernsydney.edu.au), if you would like access to your information.

We will store all information collected for this study securely and destroy it 15 years after the results are published in accordance with university policy and the Australian Code for the Responsible Conduct of Research.

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.

If you choose to withdraw, the study investigator or other staff may ask you for your reason for withdrawing to ensure we follow up on any unresolved issues. If you withdraw, you can advise us that you do not consent for us to use the data we collected up until your withdrawal. We will only use the information that you give consent for us to use.

Whatever your decision, it will not affect your medical treatment or your relationship with the medical or other staff involved in the study.

Can I tell other people about the study?

Yes, you can tell other people about the study by giving them the Chief Investigator's contact details (m.mardon@westernsydney.edu.au) or sending them the link to the screening survey.

What if I require further information?

Please contact Dr Kylie Steel should you wish to discuss the research further before deciding whether to participate.

Dr Kylie Steel

School of Health Science, Western Sydney University

k.steel@westernsydney.edu.au

Privacy Notice

Western Sydney University staff and students conduct research that may require the collection of personal and/or health information from research participants.

The University's Privacy Policy and Privacy Management Plan set out how the University collects, holds, uses and discloses personal or health information. Further details about the use

and disclosure of this information can be found on the Privacy at Western Sydney webpage.

What if I have a complaint?

If you have any complaints or reservations about the ethical conduct of this research, you may email the Ethics Committee through Research Services: 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 H *H16836*

Explanation of Consent

What will happen to my information if I agree to it being used in other projects?

Thank you for considering being a participant in a university research project. The researchers are asking that you agree to supply your information (data) for use in this project and to also agree to allow the data to potentially be used in future research projects.

This request is in line with current University and government policy that encourages the re-use of data once it has been collected. Collecting information for research can be an inconvenience or burden for participants and has significant costs associated with it. Sharing your data with other researchers gives potential for others to reflect on the data and its findings, to re-use it with new insight, and increase understanding in this research area.

You have been asked to agree to Extended consent.

What does this mean?

When you agree to extended consent, it means that you agree that your data, as part of a larger dataset (the information collected for this project) can be re-used in projects that are

- an extension of this project
- closely related to this project
- in the same general area of this research.

The researchers will allow this data to be used by other research projects that are similar in nature. Ethics approval to use these data will be sought prior to being used.

To enable this re-use, your data will be held at the University in its data repository and managed under a Data Management Plan. The stored data available for re-use will not have information in it that makes you identifiable. The re-use of the data will only be allowed after an ethics

Western Sydney University
ABN 53 014 069 881 CRICOS Provider No: 00917K
Locked Bag 1797 Penrith NSW 2751 Australia
westernsydney.edu.au

committee has agreed that the new use of the data meets the requirements of ethics review.

The researchers want to keep the data for 5 years for possible re-use. After this time the data will be securely destroyed.

You are welcome to discuss these issues further with the researchers before deciding if you agree. You can also find more information about the re-use of data in research in the National Statement on Ethical Conduct in Human Research – see Sections 2.2.14 - 2.2.18.

https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-20

Western Sydney University
ABN 53 014 069 881 CRICOS Provider No: 00917K
Locked Bag 1797 Penrith NSW 2751 Australia
westernsydney.edu.au