

Participant Information Sheet – Period website testers

Project Title: Menstrual period website think-aloud study

Project Summary:

Canberra Health Services has created a website to help young people learn more about their periods, and to help give you some advice on if they are “normal” and how to manage them. Our team is looking to see how well the current website works for young people, and to see what might need to be changed to make it better. We are inviting young people aged 17-25 who have had their periods start at least 12 months ago to help us evaluate the website using a technique called “Think-aloud”. This can be done either in-person (if you live in Canberra or near Westmead in Sydney) or online using your computer, tablet or mobile phone.

The study is being led by Melissa Parker from Western Sydney University and Canberra Health Services, A/Prof Mike Armour and Dr Amelia Mardon from Western Sydney University, Dr Beck O’Hara from Flinders University and Dr Abdel-Latif Mohamed from the Australian National University and Canberra Health Services.

How is the study being paid for?

This research is being funded under a doctoral research program through Western Sydney University and Fellowship funding from the ACT Government Health Directorate Research and Innovation Fund.

What will I be asked to do?

If you wish to take part in the study, you can complete the online screening survey to make sure you are able to participate and are happy to be contacted about the study. The researcher will contact you by phone to discuss the study and answer any questions you may have. After giving your consent to take part, the researcher will book a time with you to do the study.

Doing the study involves looking through the website with the researcher present, either online (through Zoom) or in-person. While you are looking through the website, you will be asked to speak your thoughts out loud so the researcher can understand how people use the website and how it can be improved.

How much of my time will I need to give?

You only need to participate once and we expect it will take around 30-60 minutes.

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

There may not be any direct benefit to you from participating apart from being able to learn more about your periods by using the website. However, people who complete the study will be offered a \$50 gift card in appreciation of their time and effort.

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

We do not expect any risks due to the fact we are looking at your experience of using a website. Some people may experience discomfort when reading or learning about periods and period problems. If you have any distress then you can pause the session, and either continue later or withdraw. If you'd like to speak to someone about your experiences you can reach out to Lifeline or a similar free service:

<https://www.lifeline.org.au/> or Kids Helpline (<https://kidshelpline.com.au/>); Reach Out (<https://au.reachout.com/>); Head to Health (<https://www.headtohealth.gov.au/>).

How do you intend to publish or disseminate the results?

Initial study findings will be used to change and improve the Canberra Health Services website for all users and support future research on menstrual period websites. The results of this research will be presented in many ways including scientific publications and conference presentations. In any publication and/or presentation, information will be provided in such a way that you cannot be identified. Improvements to the website will be available to any people with internet access.

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

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.

Extended consent

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 researchers in other related projects for an extended period of time. To enable this re-use, your data will be held at the University in its data repository and managed under a Data Management Plan. Please note that minimum retention period for data collection is five years post publication. 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 committee has agreed that the new use of the data meets the requirements of ethics review.

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

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-2018>

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 by asking the researcher (who will be present) to stop the think-aloud interview. At this point, any recording and participation can be deleted and removed from the study. Once the think-aloud interview recording has been analysed to provide new information and changes have been applied to the web pages, it will not be possible to withdraw that information. Although your contribution still remains anonymous.

Can I tell other people about the study?

Yes, you can tell other people about the study by sending the invitation link to other people or providing them with the details of the Lead Investigator, Melissa Parker, PhD Candidate.

What if I require further information?

Please contact Melissa Parker should you wish to discuss the research further before deciding whether to participate.

Melissa Parker email: 22121078@student.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 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 H16452.