



Participant Information Sheet – Guardian

Project Title: Menstrual health literacy and management of period pain in young Australian women

Project Summary:

You are being asked to consider whether your child/ward can participate in a research study being conducted by Dr Mike Armour, Professor Kath Holmes, Professor Caroline Smith, Associate Professor Tania Ferfolja, Dr Christina Curry, Dr Freya Macmillan and Kelly Parry (Research Assistant) from Western Sydney University. This study is designed to explore if using a web-based intervention (that they can do on their computer, smartphone or tablet) can help improve participant understanding of different symptoms they can have during their menstrual cycle (like pain or emotional changes), and to give participants some self-care options including diet, yoga (stretching), heat and acupressure, and see if these help reduce any period pain or other symptoms they might have.

How is the study being paid for?

This project is being externally funded by U by Kotex (Kimberly Clark) and internally funded through a partnership grant from Western Sydney University.

Why is this study being done?

Australian adolescents have low levels of menstrual health literacy, because they have limited access to high quality, evidence based, information on the signs and symptoms of menstruation; and are without information related to effective self-care and the ability to identify problematic menstrual symptoms that may require further investigation. This study will address the current gaps in menstrual health literacy and awareness to evidence-based self-care by developing a) an educational intervention that addresses these current shortcomings in menstrual health literacy and b) provide evidence based non-pharmacological options for menstrual health self-care.

The web-based intervention has been designed by a group of experts in women's health, including gynaecologists, GPs and PDHPE teachers; to improve women's menstrual health literacy. The resource may provide young women will up-to-date, practical information that could reduce the impact of period pain on wellbeing and academic performance. Improved

menstrual health literacy will improve women's understanding of health information, recognition of symptoms and health seeking behaviour.

What will the participant be asked to do?

- They will be asked to fill in some questions about their age, which state/area they live in, their current health literacy and healthy behaviours (like exercise), some questions about their period pain (if any), what kind of medication they take and how regular their menstrual cycle is. All these forms can be filled in online, from their phone, tablet or computer.
- Once you've filled in this information they will be given a website link and password that they can go to which has information on their menstrual cycle, such as what 'normal' symptoms are, what causes period pain, or heavy bleeding and when they need to see their doctor to talk about these. These are all described both on the website and in short video clips.
- They will also be given a number of options on 'self-care'. These are things they can do without needing to go and see their doctor. These include information on some dietary changes they can make, how to best use heat, some yoga postures or stretches, as well as acupuncture, where they press on certain places on their legs and feet. All of these treatments have been previously shown to help reduce menstrual pain. They will be asked to incorporate one or more of these practices into their lifestyle for the next three months. They will be able to choose which of these suits them best.
- They will get either a text message or email (their choice) on a regular basis (about once per week) to remind them to do these self-care practices.
- Each time they have a period for three months they will need to fill in a questionnaire each day they have bleeding, which just asks a question about how much pain they had, and if they took any analgesics (like Neurofen™). This will all be done online.
- At the end of the three months we will ask them the same types of questions as at the start, to see if anything has changed.
- After this has finished and only if they are interested, they can indicate if they'd like to give us more feedback as part of a focus group. This is totally optional.

How much of the participants' time will he/she need to give?

- **Self-care web based resource**

- This will require participation in a 3-month program.
- They will be asked to interact with the self-care web based resource intervention in their own time, selecting and practicing the relevant self-care management options.
- We expect this could be as little as ten minutes per week (using acupressure), up to an hour per week if you decide to do yoga. Some things, such as heat, they might wish to use for several hours at a time during their period.

- **Questionnaires**

- It is estimated that the questionnaires completed before and after will take between 20 and 30 minutes. Taking up 40-60 minutes overall.
- The questionnaire tracking their level of pain and medication usage will take approximately 1 minute per day. This will be completed during the three menstrual cycles, taking around 15 minutes.

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

Using the web-based intervention will provide participants with up-to-date, practical information and self-care that could reduce the impact of period pain and other menstrual symptoms on health and wellbeing. It will also let participants know if any of the menstrual symptoms they have, need to be discussed further with their doctor or health professional.

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

We do not foresee any risk to them when using the web-based information however; some of the topics and questions are personal in nature and relate to menstruation. If they do not wish to answer any specific question due to discomfort or personal preference, they can simply leave it blank or skip it. If this study has raised questions or concerns about their menstrual and pelvic pain there are helpful resources provided by the Pelvic Pain Foundation of Australia at <http://www.pelvicpain.org.au/information>. If they wish to speak to a counsellor you can contact Kids Helpline on 1800 55 1800, 24 hours a day.

The use of the self-care interventions; such as heat, stretching/yoga, and acupressure are all low risk. If they are concerned about undertaking gentle physical activity, such as yoga stretches, please consult their health care professional prior to undertaking this study. The use of heat (such as a hot water bottle) can carry a risk of burns if used at too high a

temperature or for too long. Strategies to reduce this risk are discussed in the web-based resource. Acupressure carries a very small risk of causing a bruise at the location of the pressure point if pressure is applied too firmly. Guidance is provided in the resources on how to ensure the correct pressure.

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 provided be disposed of?

Please be assured that only the researchers will have access to the raw data the participant will provide and that their 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 the participant from the study? Can the participant withdraw from the study?

Participation in the study is entirely voluntary and participants are not obliged to be involved. Participants may withdraw from the study at any time without giving reason. Whatever the decision, it will not affect the participant's medical treatment or their relationship to anyone involved in this study.

Can I, or the participant, tell other people about the study? *[Remove if not relevant]*

Yes, you can tell other people about the study by providing them with Kelly Ann Parry's (Research Assistant) details. They can then contact Kelly Ann Parry to discuss their participation in the research project and obtain a copy of the information sheet.

What if I require further information?

Please contact Kelly Ann Parry should you wish to discuss the research further before deciding whether or not to participate

Kelly Ann Parry, Research Assistant, email kelly.parry@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.

If you agree for the participant to participate in this study, you may be asked to sign the 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 H12599.