



Supporting Women with Learning Disabilities Experiencing Severe Period Pain: A Qualitative Study with Carers to Inform Educational Resource Development

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others, if you wish. I will use the term 'women' to refer to females and people assigned female at birth.

Thank you for reading this.

1. What is the purpose of this research project?

This research project seeks to understand the experiences & needs of carers supporting women with learning disabilities (LD) who experience severe period pain. By listening to carers' views on what may or may not be helpful, the findings of this study will aim to inform the development of educational resources, allowing us to optimise care for women with LD experiencing severe period pain. This research project is being carried out as part of an undergraduate student dissertation.

2. Why have I been invited to take part?

You have been invited to take part in this study because you are aged 18 and over and identify yourself as someone who cares (or cared for) for women with learning disabilities who experience (or have experienced) severe period pain.

3. Do I have to take part?

No, your participation in this research project is entirely voluntary and it is up to you to decide whether or not to take part. If you decide to take part, we will discuss the research project with you and ask you to sign an informed consent form. If you decide not to take part, you do not have to explain your reasons and it will not affect your legal rights.

You are free to withdraw your consent to participate in the research project at any time, without giving a reason, even after signing the consent form.

4. What will taking part involve?

If you consent to take part, you will be invited to take part in an interview lasting no more than 60 minutes. This can be completed in person or online and will be audio recorded. Audio recordings will be stored securely on the Cardiff University database & used for research purposes only. These will be transcribed within 1 month from the interview date, after which the recordings will be deleted. If the interview is conducted online, your image may be recorded if you choose to keep your camera on. You may wish to turn your camera off if you would prefer to. During the interview, you will be asked to discuss your experience & needs as a carer supporting women with learning disabilities who experience severe period pain. As the interview involves questions on menstrual health and caring for others,

some participants may find this distressing. You do not have to answer any questions you may find distressing, and you can stop the interview at any point.

5. Will I be compensated for taking part?

As a thank you for your time, you will be entered into a prize draw to win a £20 shopping voucher. One participant will be selected at random after all interviews have been completed. You should understand that any data you give will be as a gift and you will not benefit financially in the future should this research project lead to the development of a new treatment/method/test/assessment.

6. What are the possible benefits of taking part?

There will be no direct advantages or benefits to you taking part however your input will be valuable in helping us understand how we can optimise care for women with learning disabilities who experience severe period pain. People who participate in research report benefiting from the opportunity to reflect on their own experiences.

7. What are the possible risks of taking part?

Sharing experiences may be unpleasant or even distressful. You do not have to disclose information you do not want to. We can take a break at any point during the interview, and we will provide contacts for further support in the debrief (contact your GP, Samaritan, Carers UK). In the unlikely event that the researchers become aware of unethical or unsafe clinical practice, researchers have a duty to report this to your employer. Information may also be shared with relevant individuals within Cardiff University, where appropriate.

8. Will my taking part in this research project be kept confidential?

All information collected from (or about) you during the research project will be kept confidential and any personal information you provide will be managed in accordance with data protection legislation. Please see 'What will happen to my Personal Data?' (below) for further information.

In exceptional cases, the research team may be legally and/or professionally required to override confidentiality and to disclose information obtained from (or about) you to statutory bodies or relevant agencies. For example, this might arise where the research team has reason to believe that there is a risk to your safety, or the safety of others. Where appropriate, the research team will aim to notify you of the need to break confidentiality (but this may not be appropriate in all cases).

9. What will happen to my Personal Data?

Personal data, according to the General Data Protection Regulation (GDPR) means any information relating to an identifiable living person who can be directly or indirectly identified in particular by reference to an identifier. As part of this research project, the following personal data will be collected:

- Your name & contact details
- Demographic form (sex, age, gender identity, details related to your role)
- Audio recording of the interview
- Written consent form

All participants will be given a unique participant ID number (e.g. p4). Your unique ID number will be used to anonymise and link all your personal data except for the written consent form.

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. Further information about Data Protection, including:

- your rights
- the legal basis under which Cardiff University processes your personal data for research
- Cardiff University's Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner's Office

may be found at <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>

After the interview is complete, the research team will anonymise all the personal data it has collected from, or about, you in connection with this research project, with the exception of your consent form. Your consent form will be kept for a minimum of one year and may be accessed by members of the research team and, where necessary, by members of the University's governance and audit teams or by regulatory authorities. Anonymised information will be kept for a minimum of one year but may be published in support of the research project and/or retained indefinitely, where it is likely to have continuing value for research purposes.

Your participation in this study will not be finalised until you have completed the interview. You have the right to withdraw from the study at any time point up to one week after the interview. If this is the case, your data will also be withdrawn.

10. What happens to the data at the end of the research project?

The data will only be available to the research team and will only be used for research or educational purposes.

11. What will happen to the results of the research project?

The results of this research project will be written as part of a student dissertation and may be published in academic journals and/or presented at conferences. The results may help inform the development of educational resources for supporting women with learning disabilities who experience severe period pain. Any quotes obtained from the interview will be used for research purposes only. Quotes will be anonymised using a participant unique ID number. Participants will not be identified in any report, publication or presentation.

12. What if there is a problem?

If you wish to complain or have grounds for concerns about any aspect of the manner in which you have been approached or treated during the course of this research, please contact Dr Sofia Gameiro (GameiroS@cardiff.ac.uk) or the School of Psychology Research Ethics Committee, Cardiff University at the address below. If your complaint is not managed to your satisfaction, please contact the Information Commissioner's Office should you wish to complain, can be found at the following: <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, you may have grounds for legal action, but you may have to pay for it.

13. Who is organising and funding this research project?

The research is organised by Sameya Shazad & Dr Sofia Gameiro within the School of Psychology at Cardiff University.

14. Who has reviewed this research project?

This research project has been reviewed and given a favourable opinion by the School of Psychology Research Ethics Committee, Cardiff University. Secretary of the Ethics Committee, School of Psychology, Cardiff University, Park Place, Cardiff, CF10 3AT. Tel: 029 2087 0707 Email: psychethics@cardiff.ac.uk.

15. Further information and contact details

Should you have any questions relating to this research project, you may contact us during normal working hours:

- Sameya Shazad (shazads@cardiff.ac.uk)

Or

- Dr Sofia Gameiro (GameiroS@cardiff.ac.uk)

Thank you for considering taking part in this research project. If you decide to participate, you will be given a copy of the Participant Information Sheet and a signed consent form to keep for your records.