Participant Information Sheet for Mother’s Participation (Version no: THREE, date: 31.03.2015)

Study Title: An Exploration of the Impact of Period-Related Pelvic Pain on the Lives of Young Females and their Families

Researcher: Polly Langdon.

ERGO Study ID and RGO reference number: 12099 (12871 after amendments)

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

Invitation:

We would like to invite you to take part in our research. Before you decide whether you would like to take part or not, we would like you to understand why we are carrying out this research and what your participation would involve. A member of our research team is going to go through this information with you and will be happy to answer any questions you might have. Please make sure you take as much time as you need to go through this information and talk to others about it (i.e. your family or peers) if you would like.

In our research, we are interviewing children and adolescents experiencing chronic pelvic pain and their mothers. We will require your consent for your own participation as well as your consent for your daughter’s participation if she is less than 16 years old. This information sheet is relevant to your participation in the research. You will be provided with a separate information sheet that will provide details about your daughter’s participation.

The first part of this information sheet will explain why we are carrying out this research and what your participation would involve. The second part will go into some more details about the conduct of the study. Please ask us if any of the information is not clear or if you have any other questions.

**Part One**

What is the purpose of the study?

 This study is being conducted to help researchers and health care professionals to better understand how your child’s pain affects yours, your child’s and your family’s lives. We would like to find this out because so far, there is very little understanding about this. By improving how much people know about it, we may, in the future, be able to help improve the quality of care and management for girls experiencing period pain and their families.

Why have I been invited?

 You have been invited to help with our research because you are the mother of a child who experiences period pain.

Do I have to take part?

 It is up to you whether or not you would like to take part in this study. Once we have described the study and you have understood all of the information in this sheet, you can tell us whether you would like to take part or not. If you would like to take part, then we will ask you to sign a consent form. You are free to stop participating at any time in the study, even if you have signed the form. If you do decided not to take part, or you withdraw your consent, you do not have to give a reason and this will not affect the standard of care your daughter receives.

What will happen to me if I take part?

 If you decide that you would like to take part in this study then we would like to arrange one interview with you. The interview will be audio-recorded and transcribed word-for-word by the researcher.

Your interview will last for around 30-60 minutes and will be similar to a conversation. The researcher will ask you questions about your child’s pain and how it affects your child, you, and any other family members.

You can decide whether you would like the interview to take place at home, the University of

Southampton Pain Research Laboratory, or the interview can be conducted over the telephone. The Pain Research Laboratory has a sound proof room where the interviews will take place. Travel expenses, of up to £20 per participant, will be compensated.

What will I have to do?

 You will be asked to answer as honestly as possible about your experiences and feelings about your child’s pain. If you do not wish to answer anything, just let the researcher know. You will not have to discuss anything that you do not want to.

What are the possible disadvantages to taking part?

 If you feel upset at all whilst discussing your experiences, let the researcher know and she will ask if you would like to take a break from the interview. If you feel distressed at all and would like to stop then the researcher will stop the recording and the interview. If this happens there will be no penalty or consequences to you or your child. Your travel expenses will still be compensated and your child’s standard of care will not be affected.

What are the possible advantages to taking part?

 We cannot promise that there will be any advantages to taking part in this research. We hope that our findings will improve understanding about adolescent period pain and help to improve management and care in the future. All participants will be entered into a raffle where the winner will receive a prize worth approximately £20-£30.

What if there is a problem?

 Any complaint that you may have about the way you have been dealt with in the study will be addressed. Detailed information about this is presented in part two.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. Details will be provided in part two.

This completes part one. If the information in part one has interested you and you are considering participation in this research, please read part two before making a decision.

**Part Two:**

What will happen if I don’t want to carry on with the study?

 If you would like to withdraw from the study then all of the information that you have provided up until that point will be destroyed.

What if there is a problem?

 If you have any complaints about the study or the way that you have been treated in the study, then you can contact any members of the research team (details at the end of the information sheet) to let them know. The researcher you contact will try to solve the problem immediately. If you would not like to discuss the complaint with a researcher and would like to make a formal complaint then please contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 4663, email slb1n10@soton.ac.uk.

Your complaint will be taken seriously and addressed accordingly depending on the nature of the complaint.

Will my taking part in the study be kept confidential?

 Yes, all information about you will be kept confidential. The information you provide will be safeguarded. The recordings and transcripts will be kept safe on a pass-worded computer. Any names or places (or any other identifying information) will be deleted or replaced with pseudonyms (fake names).

No identifying information will be used in the report.

What will happen to the results of the research study?

 It is possible that the final report will be published. If you would like to be informed of the findings you will be able to contact any member of the research team who will be happy to provide you that information or links to the published report.

Who is funding the research?

 The Economic and Social Research Council (ESRC) are funding this research.

Who has reviewed this study?

All research is looked at by independent group of people, called a

Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the University of Southampton Research Ethics Committee.

Further information and contact details:

 If you have any further questions or would like any further details, please contact the primary researcher, Polly Langdon.

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