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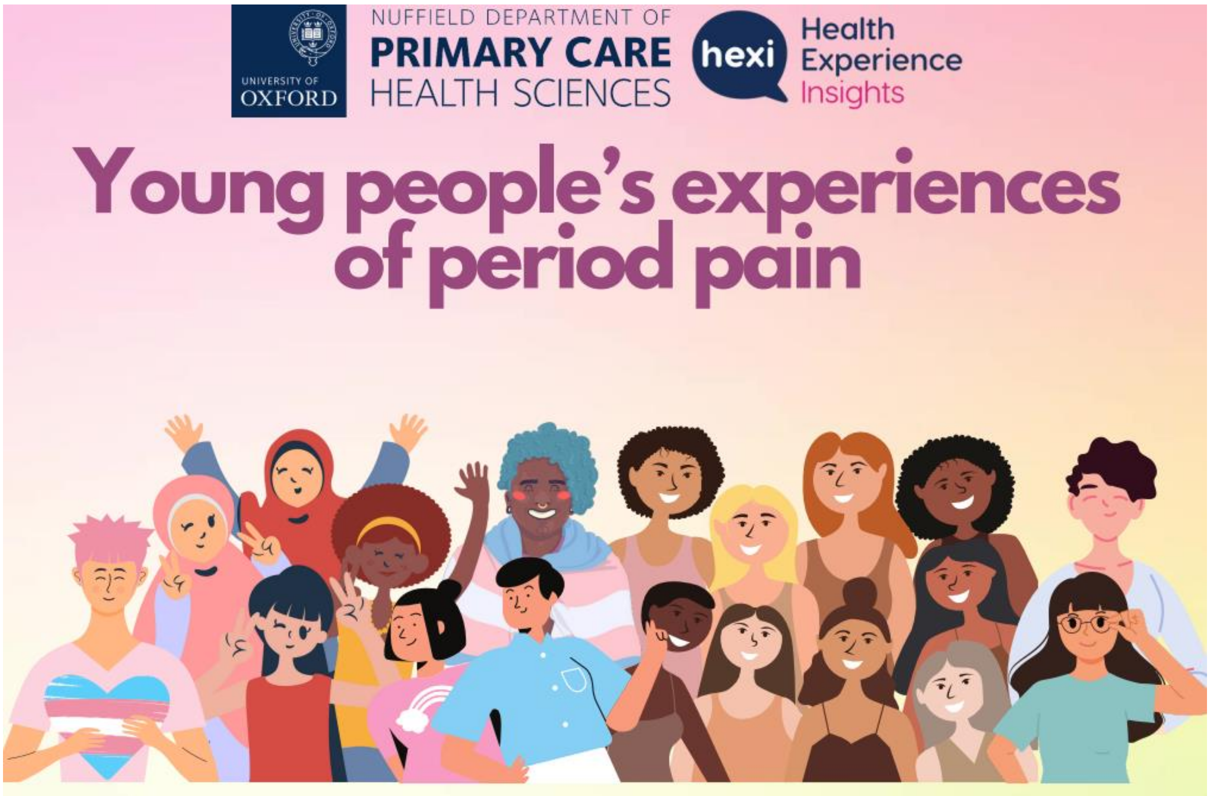
PARTICIPANT INFORMATION SHEET

TAKING PART IN AN INTERVIEW - A HEXI MODULE ON YOUNG PEOPLE'S EXPERIENCES OF PERIOD PAIN



Hello

My name Is Sharon Dixon I am a researcher from Oxford University. I am asking you to take part in research. Before you decide if you want to take part or not, I want to tell you why the research is being done, and what you can expect if you do take part. Please read what I have to say carefully. Talk about it with friends, relatives and your doctor or nurse if you wish. Ask me if you have any other questions. Please take as much time as you like to decide.
The research is being carried out as part of Sharon's PhD project, which is aiming to improve understanding and care for teenagers experiencing period pain, including in GP clinics. If you would like this information sheet in an accessible format please ask us.

Thanks for reading this.

What is the purpose of the study?

The **H**ealth **Ex**perience **I**nsights website www.hexi.ox.ac.uk has:

- people's stories of health, illness and other health related issues
- other information that may be useful to people going through similar experiences

The idea is that HEXI will help young people to:

- understand & cope with health problems and issues
- know what really matters to people when they are ill or are dealing with health issues; and
- answer common questions and provide information.

The idea is that seeing and listening to other people's experiences on the HEXI website will provide people with additional help, emotional support and practical information. Health professionals who want to understand what it is like for people to have an illness or face health choices can also visit the website. To develop each HEXI topic (such as this one) takes about one and a half years.

Anyone who has access to the Internet is able to access the HEXI website. Your interview will not be used for advertising or purely commercial purposes.

Why have I been chosen?

You have been contacted because I want to interview young people who have had experience of periods and period pain.I will be interviewing around 40 people who have had such experiences. We are interested in talking to anyone with any experience of period pain, however much it does or doesn't impact on you, whether or not you have seen a nurse of doctor, and whether or not you have tried any treatments. Your name has not been given to us at the Medical Sociology Health Experiences Research Group, so I will only be able to contact you if you fill in the patient 'reply slip' (in your information pack) and post it to us in the reply paid envelope.

Do I have to take part?

No. It is entirely up to you to decide whether or not you want to take part. If you decide to take part, you will be given this information sheet to keep. You will also be asked to sign a 'consent form'. If you decide to take part, you are still free to stop at any time without giving a reason. No questions will be asked if you stop. Deciding whether or not to take part in the study will not affect the standard of medical care you receive.

What will happen if I take part?

If you complete and send back the enclosed 'reply slip' by post or email, I will contact you to arrange an interview at a time and place that suits you. If this place is not your home, you will be paid for the cost of your travel. We can also interview by phone or email. [Optional dependent on topic/participant need: We can also offer the option of a written interview/audio diary/video diary/photo diary/ that you can complete in your own time. We will provide you with full guidance as to how to complete this and offer a secure University approved method for returning your information to us to ensure confidentiality.]

I will try to answer any questions you may have about the interview or the HEXI project. Before the interview I can show you the HEXI website. You can see how other people's interviews look in video, audio and written formats.

What would the interview be like?

I will ask you if you are willing to have the interview video or audio recorded. You will be given the 'consent form' if we meet face to face, or the researcher will complete verbal consent form if the interview is by phone or online. This form is completed if you agree to take part in the interview. You will be given, or sent a copy of the consent form to keep.

The interview will be a little like a conversation, but I will help you talk about yourself in your own words. I will ask you to talk about your experiences of period pain I will ask questions about what happened to you, what your thoughts and feelings have been at different stages, how you have got information, what you have done, and what have been the good and bad parts of the experience. If you prefer we can interview you with a friend or a member of your family.

While people sometimes find it helpful to talk about their story to researchers this research is not the same thing as counselling. However, I will give everyone a list of useful contacts which can be used to get more help if you want.

How long would the interview take?

The time it takes for an interview varies, depending on how much you have to say, but most interviews last at least an hour. If you would prefer, I can interview you on two different occasions. Remember, if you want to stop the interview at any time, you can do so without giving any reason at all.

Expenses

Any travel costs/caring expenses incurred on the day of the interview will be reimbursed. After the interview we will give you a £30 shopping voucher to say thank you for your time.

What if I decide to withdraw after the interview has taken place?

You are free to leave the study at any time. If you decide to leave after an interview has taken place, all video recordings, transcripts and typing of your interview would be destroyed. However, if you decide to leave after the website has been finished, we would remove your contribution from all later versions, but we would not be able to destroy existing material, which other people could copy from the website.

What would happen after the interview?

I will label the interview recording with a code number and give it to a typist who will type out everything you said in the interview. The typist signs an agreement to keep everything you say in the interview secret. The digital recording and the typed up record (transcript), identified only by the code number, would be kept in a secure place at the Department of Primary Care Health Sciences at the University of Oxford.

I will send you a copy of the interview transcript to help you decide whether you want your whole interview to be made available to HEXI(a recording of the interview can also be provided if requested). You would be asked to read or listen to the interview and consider if there was anything you would like to change or remove, to keep anything secret or hide your identity, or to delete or change some of your interview. You can take as long as you need to do this. You can also choose how your interview will appear on the website (see below).

How would the researcher use the interview tape and transcript?

You will be asked to sign a form '**Future use of my interview**'. If you sign this form, you give copyright of the interview to the University of Oxford. It is very important that you take time to think about this and if you wish discuss the copyright form with someone you trust, such as a family member, friend or doctor, before you sign it. This form is also used to spell out any limits that you wish to place on its use. You will be given a copy of this form to keep. The study data may be looked at by individuals from the University of Oxford, for the purpose of audit and monitoring.

If you do decide to allow your interview to be used for the HEXI website, it would be used along with interviews from other young people who have had experience of periods and period pain. A summary of these interviews would be prepared. People who use the database would be able to see the summaries of the interviews as well as read extracts from the interviews and view the video clips of people who agree to this kind of use of their interviews. All data use is strictly within the terms of the Data Protection Act (DPA 2018).

Can I choose how my interview will appear on the website?

You will have a choice about whether a video, audio or just a written version of your interview is included. If you prefer, we could use an animated image to accompany your words, including with the option of an actor speaking your words. If you want to be anonymous, you will be invited to use an alias for yourself and others, and you can keep out of the interview anything, which might identify you.
You may wish to discuss this with members of your family, since they might possibly be connected to your appearance on the screen.

You may like to discuss your interview with someone you trust (a friend, family member or professional) before deciding whether and how you would like the material to appear in any resources.

If you decide that you want your interview to be included, but do not want your own face or voice to be seen and heard, we could arrange for an actor to read your interview and be filmed and recorded for the website in your place.

If you are recognised on a website, this would be a little like appearing on the TV. And as with TV, other people can record what they find there, and show it to others. If you have any doubts about how you want the interview to be included, talk to me, or I could find an independent adviser for you to talk to if you prefer.

What will happen to my data?

Data protection regulation requires that we state the legal basis for processing information about you. In the case of research, this is 'a task in the public interest.' The University of Oxford is the data controller and is responsible for looking after your information and using it properly.

We will use information you provide in order to undertake this study and will use the minimum personally-identifiable information possible. We will keep identifiable information about you (phone and contact details) for up to three years after the HEXI study has finished. With your permission we will archive the research data (interview recording and transcript) and the consent and copyright forms securely at the University of Oxford for up to 100 years after the end of the study.
Data protection regulation provides you with control over your personal data and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate. Further information about your rights with respect to your personal data is available at https://compliance.web.ox.ac.uk/individual-rights

You can find out more about how we use your information by contacting ruth.sanders@phc.ox.ac.uk.

Who is organising and funding the research?

The Medical Sociology and Health Experiences Group based at the Nuffield Department of Primary Health Care Sciences, University of Oxford. The University of Oxford is the sponsor of the research. The project for teenager's experiences of period pain is being funded by the National Institute of Health Research (NIHR DRF NIHR301787

Contact for further information

I hope that this information sheet has told you what you need to know before deciding whether or not to take part. If you have any queries at all about the project please telephone me on sharon.dixon@phc.ox.ac.uk or on 07990515071.

Notes:

- I am a professional researcher and am paid for my work.
- The study has been approved by Berkshire Ethics Committee REC No 12/SC/0495

What if there is a problem

Given the nature of this study, it is highly unlikely that you will suffer harm by taking part, However, the University has arrangements in place to provide for harm arising from participation in the study for which the University is the Research Sponsor. If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact Sue Ziebland of the Medical Sociology and Health Experiences Research team on 01865 289302 or the head of RGEA, email ctrg@admin.ox.ac.uk

Thank you for reading this information sheet.