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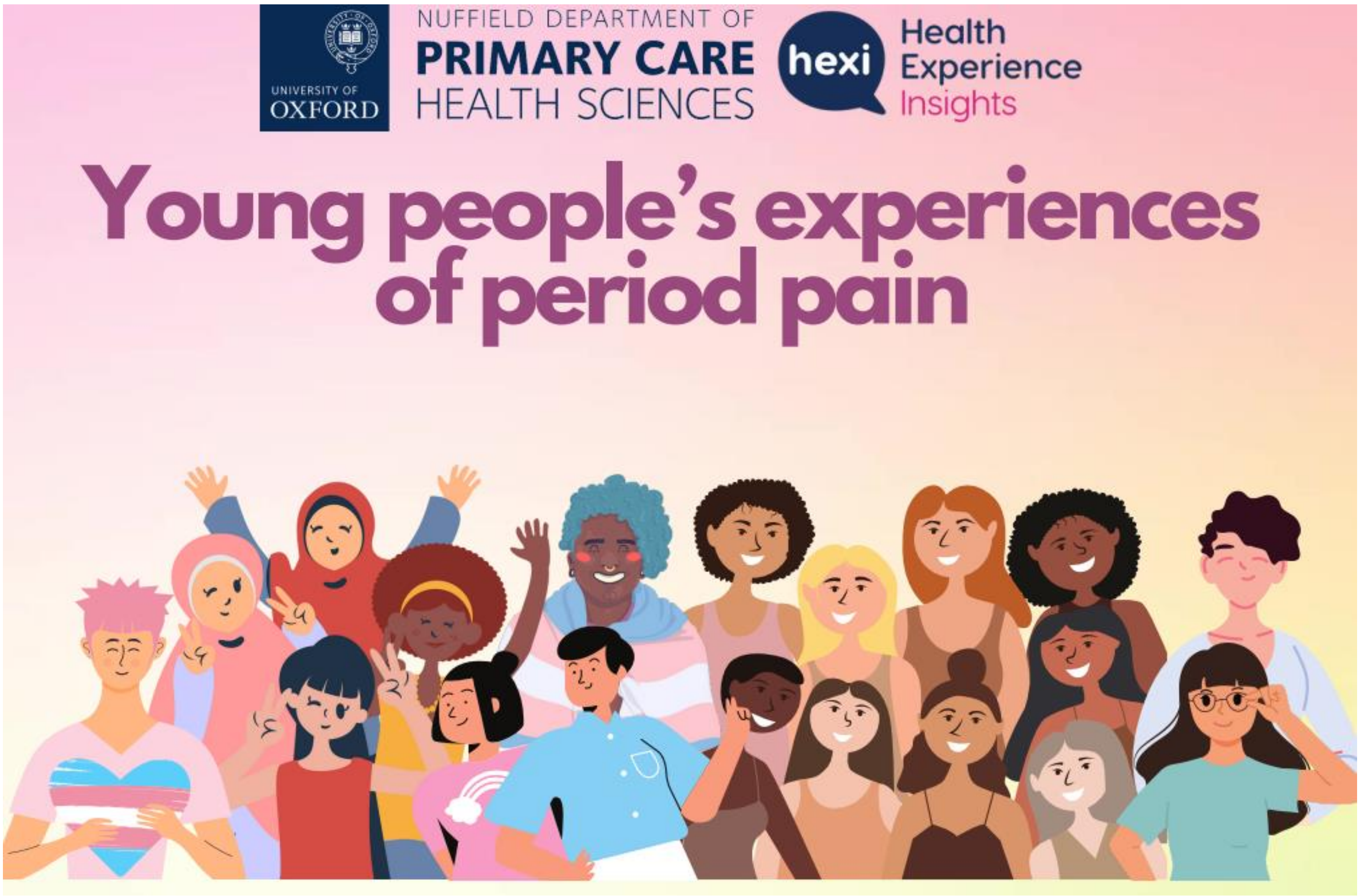
INFORMATION SHEET FOR PARENTS/GUARDIANS TAKING PART IN AN INTERVIEW - A STUDY OF EXPERIENCES OF YOUNG PEOPLE'S EXPERIENCES OF PERIOD PAIN



Hello.

My name is Sharon Dixon. I am a researcher working with the Medical Sociology and Health Experiences Research Group at the University of Oxford. I am asking your child to take part in research. Before you decide if you would like them to take part or not, I want to tell you why the research is being done, and what you can expect if they do take part. Please read what I have to say carefully. Talk about it with friends, relatives and your GP if you wish. Ask me if you have any other questions. Please take as much time as you like to decide. 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 aim of our research programme is to improve understanding of people's experiences of health, illness and healthcare, and provide resources to support people living with a wide variety of health conditions, their families, friends and the health professionals involved in their care. We collect video, audio and written interviews, which may be used in several ways:

- to find out what is important to young people who experience painful periods (menstrual pain)
- to contribute to the **H**ealth **Ex**perience **I**nsights website www.hexi.ox.ac.uk website which is run by the study team at the University of Oxford
- to develop other support and information and training resources for people
- to train health and social care professionals
- to support quality improvement in healthcare
- to write research papers

www.hexi.ox.ac.uk is a website that has:

- people's stories of health, illness and other health-related issues
- information about tests and treatments
- other information that may be useful to people going through similar experiences
- a teaching and learning area for health and social care staff and anyone involved in healthcare

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 and social care professionals, researchers and policy makers, who want to understand people's experiences can also visit the website. Anyone who has access to the Internet is able to use the HEXI website.

The interviews we collect contribute to the information presented on the sites, and extracts from many of them will be used to show what it is like for people facing illness or health issues. The interview will not be used for advertising or purely commercial purposes.

As well as the website, we may use interviews to help create other information and support resources, such as short films. These may for example be shown to people by health professionals as part of their care or they may appear on other websites approved by the University of Oxford

Interviews may also be used to develop other resources for members of the public, patients and families, for health and social care professionals and for clinical research staff, so they can learn from people's experiences and improve the care they provide. Training materials may be presented on the teaching and learning area of the www.hexi.ox.ac.uk website and on other approved websites. All the interviews we collect also contribute to research articles and papers.

Why have we been chosen?

You have been contacted because I want to interview children aged 10-15 who have had experience of health issues and decisions such as theirs. I will be interviewing a range of children who have had such experiences. We are interested in talking to any young people with experience of period pain, however much it does (or does not) impact on them, whether or not they have seen a nurse of doctor, and whether or not they have tried any treatments. Your name /your child's name has not been given to us at the Medical Sociology and Health Experiences Research Group, so I will only be able to contact you if you complete and return the 'reply slip' (in your information pack) and return it to us by post (using reply paid envelope) or by email.

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

Do they have to take part?

No. It is entirely up to you and your child to decide whether or not to take part. If they decide to take part and you consent to this, you will be given this information sheet to keep. You will also be asked to complete a 'consent form' and your child will be asked to give their assent also which is recorded on the consent form. They are still free to stop at any time without giving a reason. No questions will be asked if they stop. Deciding whether or not to take part in the study will not affect the standard of any medical care they receive.

What will happen if my child takes part?

If you complete and send back the enclosed 'reply slip' to me by post or email, I will contact you to arrange an interview at a time and place that suits you and your child. If this place is not your home, you will be paid for the cost of your travel. We can also interview by phone or online. We can also offer the option of a written interview/audio diary/video diary/photo diary/ that your child can complete in their own time. We will provide them with full guidance as to how to complete this and offer a secure University approved method for returning the 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 and your child the HEXI website. You can see how clips from other people's interviews look in video, audio, animated, and written formats.

What would the interview be like?

I will ask you and your child 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 a verbal consent form if the interview is by phone or online. This form is completed if you both agree to your child taking 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, in which I will ask your child to talk about their experiences of [name of topic] in their own words. I will ask questions about what happened to them, what their thoughts and feelings have been at different stages, how they have got information, what they have done, and what have been the good and bad parts of the experience.

How long would the interview take?

The time it takes for an interview varies, and children are able to choose how long they would like the interview to last. If you would prefer, I can interview your child on two different occasions. Remember, if your child wants to stop the interview at any time, they can do so without giving any reason at all. Your child can bring a friend or family member to the interview and you can choose where the interview takes place. We can also interview by phone or online.

Expenses

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

What if you and your child decide to withdraw after the interview has taken place?

You give your consent for your child to take part, and your child gives their assent also. Your child is free to leave the study at any time. If you /they decide to leave after an interview has taken place, all video recordings, transcripts and typing of your interview would be destroyed. If you/they decide to leave after the website or other audio-visual resources have been finished, we would remove their contribution from all later versions, but we would not be able to destroy existing material, which other people could already have seen or copied.

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 your child said in the interview. The typist has signed an agreement to keep everything they 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 Nuffield Department of Primary Care Health Sciences at the University of Oxford.

I will send you a copy of the interview transcript to help you and your child decide whether you want their interview to be made available to use for our research, including on HEXI and other audio-visual resources. A copy of the interview recording can also be provided if requested. Your child would be asked to read or listen to the interview and consider if there was anything they would like to change or remove, to keep anything secret or hide their identity, or to delete or change some of their interview. We can remove any sections that they do not want us to use. They can take as long as you need to do this. They can also choose how their interview will appear in any resources we produce (see below). Parents or legal guardians are required to sign the copyright form which indicates this.

How would the researcher use the interview tape and transcript?

You and your child will be asked to sign a form '**Future use of my interview**'. If you both sign this form, you give copyright of the interview to the University of Oxford. It is very important that you and your child take time to think about and discuss the copyright form before you sign it. You will be given a copy of this form to keep.

If you do decide to allow your interview to be used for the study, it would be used along with interviews from between 30 and 40 other children who have experiences of periods and period pain. A summary of these interviews would be prepared for the HEXI website. People who use the site 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). The study data may be looked at by individuals from the University of Oxford, for the purpose of audit and monitoring.

Can we choose how the interview will appear?

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

If they are recognised on a website or a DVD, this would be a little like appearing on the TV. The material on the website is protected by copyright and people are not allowed to copy or record what they find there but it is possible that they could. 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 and your child provide in order to undertake this study and will use the minimum personally-identifiable information possible. We will keep identifiable information (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 has reviewed the study?

This study was given a favourable ethical opinion for conduct by the Berkshire Ethics Committee.

Who is organising and funding the research?

The Medical Sociology and Health Experiences Research Group is based at the Nuffield Department of Primary Care Health Sciences, University of Oxford. The project about 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 you and your child decide whether or not to take part. Your child has been provided with their own information sheet about the project. If you have any queries at all about the project or wish to make a complaint please telephone Sharon Dixon on 07990515071 or Sue Ziebland of the Medical Sociology and Health Experiences Research team on 01865 289302.

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 your child 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 or your child 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.

Many thanks for reading this information sheet.

Sharon Dixon