



NUFFIELD DEPARTMENT OF
PRIMARY CARE
HEALTH SCIENCES



Medical Sociology and Health Experiences
Research Group • Nuffield Department of Primary
Care Health Sciences • University of Oxford •
Radcliffe Observatory Quarter • Woodstock Road
• Oxford OX2 6GG • www.phc.ox.ac.uk

+44 (0)1865 289328 • hergadmin@phc.ox.ac.uk
www.hexi.ox.ac.uk

INFORMATION SHEET

HEXI: Young people's experiences of Period pain



Hello, my name is Sharon. 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, please:

- Read this leaflet carefully
- Show this leaflet to your parents (or legal guardian) and discuss your decision with them
- Ask me if you have any questions – my contact details are at the top of this page



Please take as much time as you like to decide

If you would like this information sheet in a different format please let us know.

WHAT IS HEXI ?

www.hexi.ox.ac.uk is a website containing:

- people's stories of health, illness and lifestyles
- information about tests and treatments
- links to support groups & websites

WHY ARE YOU DOING THIS PROJECT?

The Health Experience Insights website www.hexi.ox.ac.uk aims to:

- help young people understand & cope with health problems and lifestyle choices
- help parents, doctors, and nurses understand what really matters to young people
- answer common questions and provide information that can help young people make health and lifestyle choices

Anyone who has access to the Internet can use the HEXI website.

WHO IS DOING 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 for young people's experiences of period pain is funded by the National Institute of Health

Research (S Dixon DRF NIHR301787)



DO I HAVE TO TAKE PART?

No, it is your choice. If you decide to take part, you can stop at any time and we will not ask you why.

IF I TAKE PART WHAT WILL I HAVE TO DO?

I would like to interview you and to record our conversation. When we do the interview, I will:

- Show you the website
- Answer your questions
- Check that you have read this information sheet
- Ask permission to record your interview
- Give you an 'assent form' - you only complete this form if you agree to take part in the interview

We also ask your parent or guardian to complete a 'consent form' as well.

CAN I CHOOSE HOW MY INTERVIEW WILL APPEAR ON THE WEBSITE?

Yes. People who use the website will be able to see the summary of your interview and extracts from your interview in one of the following ways – the choice is yours:

1. We could use video or audio extracts from your interview – people will see you or hear your voice on the website.
2. We could use written extracts from your interview – people will only be able to read what you told me.
3. An actor could speak your words.
4. An animated image could speak your words, using your voice or the voice of an actor

Before the website is available to the public, you can check the clips that we have used from your interview. If you don't like them, you can ask us to remove them or to record them again with an actor or animated image.

Please discuss your choices with members of your family, because they might be linked to your interview on the website. 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 have any doubts or concerns, talk to me, or I can find someone independent for you to talk to.

WHAT'S THE ACTUAL INTERVIEW LIKE?

The interview is like a conversation, but I help you talk about yourself in your own words.

I will ask questions about:

- your experiences, thoughts and feelings
- how you got information
- the good and bad parts of your experience

You don't have to answer all my questions and you can stop at any time, without giving a reason.



You can also:

- Bring a friend or family member if you want
- Choose how long the interview lasts

Choose where (home, school, somewhere else), when and what time we do the interview - I will pay for any special journeys you make. We can also do interviews by telephone or online. 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.]

After the interview I give everyone a list of useful contacts, websites and information. I will give you a £30 shopping voucher to say thank you for your time.

WHAT DO YOU DO WITH MY INTERVIEW?

1. I label the recording with a code number and a typist types out everything you said. (The typist signs an agreement to keep everything you say in the interview secret.) Everything is kept in a secure place at the University of Oxford.
2. I write a summary of your interview and send this to you to check.
3. I send you a copy of your interview on paper or CD. You can decide if there is anything in your interview that you would like to change, remove, or keep secret.
4. You can choose a false name for yourself and others.
5. I give you a form ('Future use of my interview'). On this form you can tell us how we can and can't use your interview (see below). Your interview will not be used for advertising or purely commercial purposes.
6. If you sign this form, you give copyright - the right to copy and use your interview - to the University of Oxford. Please take time to think about this form before you sign it. I will also ask your parent or guardian to sign this form.

All data use is strictly within the terms of the General Data Protection Regulation (GDPR) and Data Protection Act 2018.

IF I DECIDE TO TAKE PART, WHAT SHOULD I DO NEXT?

1. If you and your parents/guardian are interested in the study fill in the participant 'reply slip' and post it to us in the reply-paid envelope (in your information pack), or return by email.
2. I will contact you to arrange an interview.

WHAT IF I CHANGE MY MIND?

You are free to leave the project at **any time**. If you leave after your interview, we will destroy all recordings, transcripts and typing of your interview. If you leave after the website has been finished, we will remove all your information from the site, but we will not be able to destroy anything that other people had already copied from the website.

I STILL HAVE SOME QUESTIONS...

For more information or to make a complaint, please contact:

1. Sharon Dixon, Researcher –
email: sharon.dixon@phc.ox.ac.uk telephone: +447990515071
2. Sue Ziebland, Research Director –
email: sue.ziebland@phc.ox.ac.uk
telephone: 01865 289328

Many thanks for reading this information sheet!

Notes:

- 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 Health Experiences Research team on 01865 289302 or the head of RGEA, email ctr@admin.ox.ac.uk