FUNDED BY

NIHR | National Institute for Health and Care Research

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

PARTICIPANT INFORMATION SHEET

TAKING PART IN AN INTERVIEW - A STUDY OF EXPERIENCES OF POSTNATAL CARE AND HYPERTENSIVE DISEASE IN PREGNANCY AMONG UNDER-REPRESENTED WOMEN AND BIRTHERS’

Hello

My name is Layla Lavallee. I am a researcher working with the Medical Sociology and Health Experiences Research Group at the University of Oxford. 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, healthcare providers or any other support person if you wish. Ask me if you have any other questions. Please take as much time as you like to decide. This research is being carried out as part of a doctoral research project. 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 people faced with different health issues
- to contribute to the **H**ealth **E**xperience **I**nsights website www.hexi.ox.ac.uk 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 such as bereavement, ageing or parenting
- 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 site, and extracts from many of them will be used to show what it is like for people facing illness or health issues. Your 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 I been chosen?

You have been contacted because I want to interview people who have had experience of hypertensive disease in pregnancy. I will be interviewing a range of people who have had such experiences. I am specifically interested in talking to minority ethnic women and/or those facing challenges such as poverty, mental health difficulties, substance abuse problems or domestic abuse. These characteristics cover a wide range of experiences, however people who meet these criteria can find it more difficult to get the healthcare information and support they need and are therefore collectively referred to as "underserved" in this study. If you feel this applies to you then you, and you've had high blood pressure or pre-eclampsia during or just after pregnancy then you would likely be eligible for this study. Your 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 contact me by email, phone or text or complete and return the 'reply slip' (in your information pack) and return it to us by post (using 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 complete 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 contact me by email, text or phone or complete and send back the enclosed 'reply slip' to me by post, 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 telephone or online or 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 clips from 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 compete a verbal consent form if the interview is by phone or online. You only complete this form if you agree to take part in the interview. You will be given a copy of the consent form to keep.

The interview will be a little like a conversation, in which I will help you talk about yourself in your own words. I will ask you to talk about your experiences of postnatal care and hypertensive disease in pregnancy. I will ask questions about what happened to you, what your thoughts and feelings have been at different stages, how you have gotten information, what you have done, and what have been the good and bad parts of the experience.

While people 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 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 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. If you decide to leave after the website or other audio-visual resources have 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 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 you said in the interview. The typist has signed 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 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 decide whether you want your 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. 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. We can remove any sections that you do not want us to use. You can take as long as you need to do this. You can also choose how your interview will appear in any resources we produce (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 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 ten and twenty other people who have experiences of hypertensive disease in pregnancy. 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 I choose how my interview will appear?

You will have a choice about whether a video, audio or written version of your interview is included. We may be able to offer that an actor would speak your words on video. 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.**

If you are recognised on a website, 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 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 has reviewed the study?

This study was given a favourable ethical opinion for conduct by the Berkshire Ethics Committee REC No 12/SC/0495.

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; Exploring the Postnatal Care Experiences of Underserved Women/Birthers' with Hypertensive Disease in Pregnancy - An Intervention Development Study is being funded by the National Institute for Health and Care Research.

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 or wish to make a complaint please telephone Layla Lavallee on 07795 390 269 or Sue Ziebland of the Medical Sociology and Health Experiences Research team on 01865 289 302.

Notes:

- I am a professional researcher and am paid for my work.
- The study has been approved by Berkshire Ethics Committee REC Ref 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.

Many thanks for reading this information sheet.

Layla Lavallee