

**How do women with obsessive
compulsive disorder experience
mental health care and maternity
care during pregnancy and
postpartum**

Participant Information Sheet



We'd like to invite you to take part in our research study. It is important that you understand why the research is being done and what it would involve for you. This information sheet explains why we are carrying out these interviews so you can decide if you would like or take part. Please ask us if there is anything that is not clear or if you'd like more information.

Why is this research being done?

We are researching what mental health care and maternity care is like for women with OCD during pregnancy and postpartum. We want to understand your personal experiences about the health care and maternity care you received during your pregnancy and postpartum, so will ask you to take part in an interview where we will talk about your experiences and how you feel about them. Very little research has been done on this topic before and we want to understand it better to.

Why have I been invited?

You have been invited to participate in this study because you have OCD and have given birth in the past two years, and because you recently took part in a survey about maternity care experience and you indicated that you would like to discuss this further during an interview.

We are intending on interviewing 25-30 participants during this study all of whom have OCD and have given birth in the past two years.

What is OCD?

OCD is a mental health disorder that is characterised by obsessions and compulsions, where obsessions are repetitive intrusive and unwanted thoughts, images or urges, and compulsions are the mental or physical repetitive acts that the individual feels compelled to do in response to the obsession. OCD affects at least 1 in 50 pregnancies in the UK.

Do I have to take part?

No, you do not have to take part. Your involvement in this study is entirely voluntary. Not taking part will not affect you adversely in anyway. You are also able to withdraw your consent during the interview and the interview will stop. You

do not have to give a reason for withdrawal. If you have already taken part in an interview, you can withdraw the interview up to 7 days later.

What happens if I decide to take part?

If you agree to take part in this study,

1. You will be asked to take part in an audio recorded interview at a time that suits you. At the start of the interview you will be asked to consent to take part in the study. This interview will last as long as you would like it to, however on average this will take between 45 minutes and an hour. It will be very informal. This will be recorded by the researcher and they will securely email you a copy of the consent form. During the interview, the interviewer will ask you questions about your experience of mental health care and maternity care during pregnancy and after you gave birth. At the start of the interview you will also be asked some questions about your OCD during pregnancy and during the year after you gave birth generally so the interviewer can fill out a standardised OCD scale tool, this is to determine if you meet the threshold for inclusion in this study. If you do not meet this threshold, it will be a shorter interview and your interview data will be used to provide valuable context data for the study findings alongside your survey data.
2. It can be difficult talking about these types of experiences, and your wellbeing is of utmost importance to us. You are welcome to take a break at any point in the interview, or to reschedule it for another time, the interviewer will also check in with you if you seem distressed and remind you that you can take breaks. At the end of the interview, you will be sent a resources list which will have a list of places you can contact if you feel that you need support after the interview. You will also be asked if you would like to be sent a summary of the results at the end of the study.

Where will interviews take place?

Interviews will take place online or face to face depending on your preference and location. If you live in Oxford, you have the option of having a face to face interview in an interview room at Old Road Campus, OX3 7DQ

What should I consider?

For the study to be appropriate for you, you need to:

- be 18 years old and above
- have given birth within the past two years

- have OCD during pregnancy or up to one year postpartum: self-identified or received a diagnosis of OCD from a mental health professional or received treatment for OCD during pregnancy or postpartum.
- be/have been living in the UK during their pregnancy and the year after birth.
- be willing and able to give consent to participate in the study.

Are there any possible disadvantages or risks from taking part?

As you will be answering questions about potentially vulnerable and upsetting times in your life you may find that the questions you are asked are triggering or distressing. The interviewer, Hollie Burton, will be mindful that these are difficult questions to answer and will ask if you would like to pause or stop the interview if you are particularly distressed. You will be given a debrief sheet outlining places of support that you can access if you are distressed by this experience. If Hollie is concerned about you or your baby, with your permission she will pass your details on to her supervisor Professor Paul Salkovskis, who is a clinical psychologist as Oxford NHS Foundation Trust. Professor Salkovskis will then contact you to discuss with you the next steps that could be taken to get you the help that you might need. In the unlikely event that you are in immediate danger, Hollie will recommend that you call 999 if the interview is taking place online, or she will call 999 if it is a face to face interview, she will then contact Professor Salkovskis as above.

Hollie has experience of interviewing women with OCD about their experiences of pregnancy, therefore, she understands that this is a sensitive topic and that it can be difficult to talk about these experiences.

She aims to create a welcoming and non-judgmental space for you to talk about your experiences.

What are the possible benefits of taking part?

There is no benefit to you, though this will hopefully provide a safe non-judgmental space for you to tell your story in.

Will I be reimbursed for taking part?

You will be given a £15 voucher for your time taking part in this study. If you have had to travel for the interview, travel expenses can be reimbursed.

Will my General Practitioner/family doctor (GP) be informed of my participation?

Involvement in this study will not affect any clinical care that you may be receiving or receive in the future and therefore your GP will not be notified of your involvement in this study. As noted above, if there are concerns about you or your baby and you decide to speak to Professor Salkovskis, the interviewer will pass on your contact details so that he can contact you to discuss the details of your situation, he may suggest that you be referred to other health professionals with your permission.

Will what I say be kept confidential?

Everything you say will be kept confidential (private) between you and the research team. Only audio input will be recorded on a digital recording device. Audio recordings will be confidentially transcribed by a professional transcriber and then the recordings will be deleted. Only a professional transcriber and the researchers will hear what you say. We will take out any names and any identifying information about you. We may use quotations from what you say and discuss your ideas and experiences in articles or reports, but we won't ever use your name or other information that can identify you or your baby/babies. Responsible members of the University of Oxford and Oxford Health NHS Trust Foundation may be given access to data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

What will happen to my data?

Data protection law requires that we tell you 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 which means it is responsible for looking after your information and using it properly.

We will be using information from you in order to undertake this study and will use the minimum personally-identifiable information possible.

All the information you give us will be kept securely and confidentially on servers at Oxford Population Health (The Nuffield Department of Population Health). Audio files and transcripts of interviews will be shared via secure document sharing between the transcriber and researcher. The audio will be destroyed once the transcript has been produced.

At the end of the research, anonymised data and consent forms will be securely stored for 10 years at the University of Oxford. We will keep your contact details for up to 12 months in order to send you a summary of what we have found. Any other personal information will be securely destroyed at the end of the research.

Data protection law gives you 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 Hollie Burton (hollie.burton@ndph.ox.ac.uk)

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

You can stop the interview at any time and withdraw from the study without giving a reason by telling the interviewer that you would like to withdraw. If you withdraw during the interview the interview will stop. You can ask for the data that has been collected up till this point to remain in the study or for it to be deleted. If you have already taken part in an interview, you can withdraw the interview up to 7 days later and your data will be destroyed. You can withdraw by emailing hollie.burton@ndph.ox.ac.uk and asking to withdraw your information. After 7 days, analysis of your data will begin at which point it will not be possible to separate your data from the data set.

What will happen to the results of this study?

It will not be possible to personally identify you in any report or publication that is written as a result of this study. The results of this study will be published in a doctoral thesis to fulfil the requirements of Hollie Burton's postgraduate Doctor of Philosophy degree (DPhil). Research findings will also be published in journal articles and presented at conferences; this may include direct quotes that do not identify you. If you have indicated that you would like to be sent a summary of the results this will be emailed to you.

What if there is a problem?

The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

If you wish to complain about any aspect of the way you have been approached or treated, or how your information is handled during this study, you can contact my supervisor Fiona Alderdice on 01865617901 or fiona.alderdice@npeu.ox.ac.uk, or the University of Oxford Research Governance, Ethics & Assurance (RGEA) at rgea.complaints@admin.ox.ac.uk or on 01865 616480.

How have patients and the public been involved in this study?

When designing this study, we had two women with OCD who have had a baby help advise us on the study, this was to help us ensure that this study is useful and meaningful to the OCD community. We consulted them on a range of topics including the questions that should be asked during the interview and all of the documents participants are given.

Who is organising and funding the study?

We are researchers in the National Perinatal Epidemiology unit in the Nuffield Department of Population Health at the University of Oxford.

The research team:

Hollie Burton (DPhil Population Health Student), Fiona Alderdice (Senior Social Scientist), Claire Carson (Senior Epidemiologist) and Paul Salkovskis (Clinical Psychologist)

This research is being carried out as part of Hollie's doctoral studies which are funded by the Department of Population Health.

This study is sponsored by the University of Oxford.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by East of Scotland Research Ethics Service (EoSRES).

Further information and contact details:

We know it can be difficult talking about these topics so if you have any questions

Please contact Hollie Burton by email: hollie.burton@ndph.ox.ac.uk

01865 289726

Thank you for considering taking part.



Nuffield Department of Population Health
University of Oxford
Old Road Campus
Oxford
OX3 7LF



JC/24/ES/0027