OXFORD POPULATION HEALTH
UNIVERSITY OF OXFORD
NPEU

How do women with obsessive compulsive disorder experience 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 this survey 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 maternity care is like for women with OCD during pregnancy and up to a year after birth (postpartum). We want to understand your personal experiences about care you received during your pregnancy and postpartum, so will ask you to take part in a short survey to help us understand what maternity care is like for women with OCD. Very little research has been done on this topic before and we want to understand it better.

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.

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.

Do I have to take part?

No – it's up to you. You can ask questions about the study before deciding whether or not to participate. If you do agree to participate, you may withdraw yourself and your data from the study at any time, without giving a reason and without penalty, by exiting the survey and not submitting the survey.

What happens if I decide to take part?

If you agree to take part in this study,

You can take part in the survey, which is at the bottom of this webpage. It will take about 30 minutes. The survey asks questions about your experiences of maternity care. It also asks some questions about you (your age, education, ethnicity, whether you have a partner). It will also ask you some questions about whether you have an OCD diagnosis from a health professional and when your symptoms started. These personal questions are to help us understand more about the women who take part in the survey.

You don't have to answer all the questions if you don't want to. You can change your mind about taking part and stop at any time, and nothing will happen if you do.

You also have the option to enter your email address at the end, if you want to be sent a copy of the summary of the results of this study or to contact you to invite you to take part in an interview to discuss this topic further.

What should I consider?

In order to participate in this research, 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?

Talking about maternity care experiences may be difficult, especially if you did not feel well supported during your pregnancy or postpartum. At the end of this sheet and at the end of the survey there will be a list of organisations you can get support from if this survey brings up anything distressing for you.

What are the possible benefits of taking part?

There are no direct benefits to you in taking part in this study though this will hopefully provide a safe non-judgmental space for you to tell your story in.

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. Therefore, your GP will not be notified of your involvement in this study.

Will what I say be kept confidential?

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 collected through the secure online data collection system called JISC will be kept securely and confidentially on servers at Oxford Population Health (The Nuffield Department of Population Health)

At the end of the research, anonymised data and consent forms will be securely stored for 10 years at the University of Oxford. If you provide contact details, either to participate in interview or to receive a summary of what we have found out, these will be held for up to 12 months after the end of the study so we can send you the summary.

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 withdraw from the study without giving a reason. To withdraw you can leave the survey at any time and not submit your responses. Although you may decide to give us identifiable information at the end of the survey for a follow-up interview, the link between your survey data and your identifiable information will be broken quickly so it will not be possible to identify your data to remove it after you have submitted it.

What will happen to the results of this study?

It will not be possibly 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 have been anonymised. 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 survey 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.

Here is a list of places you can contact for further support:

Your general practitioner (GP)

OCD-action, Monday to Friday 9.30am-8pm:
0300 636 5478
or email *support@ocdaction.org.uk*
https://ocdaction.org.uk/

OCD-UK, Monday to Friday 9am-12pm:
01332 588112 or email through website *https://www.ocduk.org/contact-us/*

The Samaritans, 24 hours:
116 123 (this is a free telephone number and will not appear on the phone bill)
or email *jo@samaritans.org*
www.samaritans.org

For urgent medical help:

NHS 111 service: 111

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