



Methods of Assessing Perinatal anxiety (MAP)

Participant Information Sheet

Introduction

We'd like to invite you to take part in our research. We are a team of researchers from City, University of London and the University of Stirling, and we are interested in your experiences during pregnancy and after birth and the best way to assess anxiety and mental health. Before you decide it is important that you understand why the research is being done and what it would involve for you. If anything is unclear, you can ask us any questions or talk to others about the research if you wish.

Why are we doing the research?

Women who are pregnant, or have recently had a baby are often asked how they are feeling by their midwife and/or health visitor. This is to identify any issues with anxiety and mental health. There are a number of different questionnaires that can be used, however, we do not know which work best, or when the best time for women to complete them is. Especially as some women will not have symptoms. In this research we are trying to find out women's experiences during pregnancy and after birth. We want to find out which questionnaires are best at identifying women who need help. We also want to find out when in pregnancy, or after birth, these questionnaires are most effective at identifying this need.

Why have I been chosen?

You are invited to take part in this research because you are a pregnant woman. To be eligible you must be aged 16 or older, and less than 15 weeks pregnant.

Do I have to take part?

No, it is up to you to decide to take part or not. This will not affect your care in any way. You may also want to talk to your family about it before making your decision.

What will happen to me if I take part?

If you would like to take part you should complete the consent form and anxiety and mental health questionnaire, and return them to the Pregnancy MAP research team.

There are 4 questionnaires to complete in total at approximately 12, 22 and 31 week's pregnancy, and 6 weeks after you have given birth. These can be completed online, or by filling in paper copies and returning them to the research team in a secure reply-paid envelope. Each questionnaire should take approx. 10 minutes to complete. Before we send you each questionnaire, we would like to check some information about you with your clinical care team. This will involve looking at your maternity records.

If your responses suggest that you are suffering from anxiety or depression we will contact you and provide details of organisations that can offer support.

Some women will also be asked some questions by telephone once because we would like to talk with women of different ages and cultures who have had different experiences. This will take approximately 10-15 minutes. It is your choice whether you take part in this, or if you just want to take part in the questionnaire study.

What are the possible benefits of taking part?

There are no specific benefits for you if you do take part. However, the information we get from you may help improve the assessments of anxiety and mental health in pregnancy or after birth. This is a vital step that can lead to women getting support and treatment if they need it.

What are the possible disadvantages and risks of taking part?

There are no serious disadvantages in taking part in this research. However, some women may become distressed if they are reminded of emotional difficulties when completing questionnaires. If this is the case, you will find contact details of some helpful organisations at the end of this information sheet. We also recommend that you speak with your GP, midwife or health visitor. If you would like to contact the Chief Investigator or researchers our details are also at the end of this leaflet.

Will my taking part in the research be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. Although what you say to us is confidential, if you disclose any criminal activities, or anything which we feel puts you or anyone else at any risk of harm, we may feel it necessary to report this to the appropriate persons.

What will happen to the results of the research?

The results will be reported through conferences and published reports and academic papers. If you would like to receive a copy of the results of this research and/or its publication or be informed about future research, please let us know by indicating in the box provided on the consent form.

What if there is a problem?

If you experience any problems, or have concerns or questions about this research, please contact a member of the research team. If you remain unhappy, you can go through City, University of London's complaints procedure. For this phone 020 7040 3040 and ask for the Secretary to Senate Research Ethics Committee providing them with the title of the project "Methods of Assessing Perinatal Anxiety (MAP): the Acceptability, Effectiveness and Feasibility of Different approaches".

The Secretary can also be contacted by post and email:

Anna Ramberg

Research Governance & Integrity Manager, Research & Enterprise
City, University of London
Northampton Square
London
EC1V 0HB
Email: anna.ramberg.1@city.ac.uk

Who is organising and funding the research?

The research is funded by the National Institute for Health Research, Health Services and Delivery Research Programme (Project Number: 17/105/16). It is sponsored by City, University of London and includes healthcare researchers from 7 universities and the NHS.

Who has reviewed this research?

The following groups have reviewed this research and given their approval for it to be carried out:

- West Scotland 3 Research Ethics Committee.
- Each local NHS Board ethics committee and Research & Development department.

Can I contact a member of the research team for further information?

If you have any further questions about the research at any stage, please feel free to contact:

Dr Louise Williams

Research Fellow

Tel: 07907 806327

Email: louise.williams@city.ac.uk

Dr Rose Coates

Research Fellow

Tel: 07594 233762

Email: rose.coates@city.ac.uk

Professor Susan Ayers

Chief Investigator MAP Research Programme

Professor Maternal & Child Health

Tel: 020 7040 5834

Susan.ayers.1@city.ac.uk

Information about the research is available on the following web site:

<https://blogs.city.ac.uk/map/>

How will we use information about you?

We will need to use information from you for this research project. This information will include your name, NHS (or CHI) number and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data for up to 10 years so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving reason, but we will keep information about you that we already have. If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study. You can also agree to be contacted about long-term follow-up for a subsequent study we might carry out.

Where can I find out more about how my information is used?

You can find out more about how we use your information at:

- www.hra.nhs.uk/information-about-patients/
- Our leaflet available from www.hra.nhs.uk/patientdataandresearch
- By asking one of the research team
- By sending an email to dataprotection@city.ac.uk
- By phoning 0207 040 4000 who will liaise with our Data Protection Officer

Thank you for reading this and considering taking part in this study.

Useful Organisations

PANDAS Foundation - Pre-and post-natal depression advice and support

www.pandasfoundation.org.uk

Tel: 0843 2898 401 (helpline open weekdays 9am-8pm,

Anxiety UK - Information and support for those living with anxiety and anxiety-depression

www.anxietyuk.org.uk

Tel: 03444 775 774 (information line open weekdays 9.30am-5.30pm.

Association for Post-Natal Illness (APNI) - provides support to mothers suffering from post-natal illness

www.apni.org

Tel: 0207 386 0868 (helpline open weekdays 10am-2pm).

Tommy's - midwife-led support and information for pregnant women, and those who have suffered the loss of a baby.

www.tommys.org/mentalhealth

Tel: 0800 014 7800 (Monday to Friday, 9am to 5pm), or email midwife@tommys.org.

NCT - provides practical and emotional support about pregnancy, birth and early parenthood, including feeding.

www.nct.org.uk

Tel: 0300 330 0700 (telephone helpline weekdays 8am-midnight including bank holidays).