**Participant Information Sheet**

Evaluating PerinAtal men**T**al **H**ealth **O**nline **R**esources (PATHOR): Improving knowledge and de-stigmatising perinatal mental illness

We would like to invite you to take part in a research study. Before you decide whether to take part, we would like you to understand why the research is being carried out and what it would involve for you. Please take time to carefully read the following information and discuss it with others, if you wish.

**What is the purpose of this project?**

Becoming a parent can be an exciting time but it can also bring many challenges that could affect parents’ mental health. Perinatal mental illnesses (PMI), such as postnatal depression and anxiety, can affect both men and women but sometimes these needs aren’t accurately understood or recognised. Therefore, we have developed a hub of online resources which aims to share information about perinatal mental illness across 4 different countries: England, France, Belgium and the Netherlands. In this study, we would like to get an idea of peoples’ understanding, attitudes and experiences of PMI in England, after they have used the online hub, using an anonymous online survey. Also, in light of the current pandemic, we have included questions which aim to assess the potential impact COVID-19 may have had on peoples’ wellbeing.

**Why have I been invited to take part?**

We are asking pregnant women, mothers with children that are less than one year old and their partners, to take part in the study in order to understand their perspective on PMI.

**Am I eligible to take part?**

You do not need to have experienced PMI in order to take part in this study.

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To take part you need to be:

* aged 18 or over
* able to give informed consent
* are pregnant or have a partner who is pregnant
* have given birth or have become a parent less than one year ago
* have sufficient command of the English language
* have accessed the UK PATH hub of [online resources](http://213.171.212.212/uk/professionals-page/)

**You cannot take part if you:**

* Do not have any biological children (i.e. with adopted and/or foster children)
* Are not pregnant and all of your children are older than 1 year of age.

**Do I have to take part?**

Your participation is entirely voluntary. A decision not to take part will not affect any of the care you receive now or in the future. If you do begin the survey and decide that you no longer want to take part, you can stop the survey at any time without giving a reason. As participation is anonymous, once you have submitted your responses, it will not be possible to modify or delete them at a later date.

**What will I need to do if I take part?**

If you choose to continue, you will need to confirm that you have had a chance to read this information sheet and give your informed consent. Once you have completed this, we will ask you some questions about yourself and about your understanding, attitudes and experiences of PMI. We will also ask you about your experiences during the COVID-19 pandemic and how it has made you feel. You will be able to take as much time as required when answering these questions.

**What are the benefits of taking part?**

We cannot promise that the study will directly help you, but the information we get from this study may help us develop other services and treatments for people with PMI. Furthermore, by taking part in this survey, you may gain a better understanding of the signs and symptoms of PMI and the support available.

**What are the possible disadvantages of taking part?**

We will be asking you to give up your free time to complete the survey, which should take approximately 15 minutes.

Furthermore, some of the questions asked may be seen as sensitive in nature, if you feel uncomfortable you can stop the survey at any time. At the end of the survey, we will provide you with details for services to help if you have feelings of distress. These details are also included at the end of this information sheet.

**What are your choices about how your information is used?**

The survey is anonymous, so we will not be collecting anything that will identify you to us; such as your name, contact details or computer Internet Protocol (IP) address.  You can stop the survey at any time, without giving a reason. After you have completed and submitted the survey, it will not be possible to identify or remove your data because your responses will be anonymous. Your anonymised data may be kept for use in future research and shared with other institutions in the UK and abroad.

**Where can you find out more about how your information is used?**

You can find out more about how we use your information

* at [www.hra.nhs.uk/information-about-patients/](https://www.hra.nhs.uk/information-about-patients/)
* our leaflet available from [**www.hra.nhs.uk/patientdataandresearch**](http://www.hra.nhs.uk/patientdataandresearch)
* by asking one of the research team
* by sending an email to Leanne Mcdougall, Head of Information Governance [leanne.mcdougall@nhs.net](mailto:leanne.mcdougall@nhs.net) or phone 01795 514507 or by ringing us on 01622 427 211

**How will my data be stored?**

This study will comply with the Data Protection Act 2018. All information will be kept confidential and will be stored for 10 years. The information that you give us will be stored anonymously in a secure, password protected, online database held at Artesis Plantijn University College (AP). This database will be supported by AP infrastructure, in compliance with AP data security policy.

**What will happen to the results of the study?**

We hope to present the results of this study at both national and international conferences and may it be published in scientific journals. The data that you provide is anonymous, and you will never be named or identified in any publication resulting from this research. Once the wider project has completed, and a summary of the results will be accessible on the KMPT website and on KMPT social media:

Website: <https://www.kmpt.nhs.uk/get-involved/research/home-grown-research/pathways-to-improving-mental-health/>

Twitter: [@KMPT\_Research](https://twitter.com/KMPT_Research)

Facebook: <https://www.facebook.com/kmpt.nhs/>

**Who is organising and funding the research?**

The study is organised and sponsored by Kent and Medway NHS and Social Care Partnership Trust (KMPT) in collaboration with Artesis Plantijn University College (AP) in Belgium. The project is funded by Interreg2seas who support joint cross-border cooperation projects between organisations based in England, France, Belgium and the Netherlands.

**Who has reviewed the study?**

All research in the NHS is reviewed by an independent body called a Research Ethics Committee; this is to protect your rights, safety, dignity and wellbeing. This study has been reviewed and approved by West Midlands - South Birmingham Research Ethics Committee (reference number: 21/WM/0198), as well as the Health and Research Authority (HRA) who have assessed the governance and legal compliance for this study.

**Contact details**

If you have any further questions about this research please contact us using the details below:

|  |  |  |  |
| --- | --- | --- | --- |
| **Role** | **Name** | **Email** | **Telephone** |
| **Chief investigator** | Dr Bosky Nair | Bosky.nair1@nhs.net | 01622 722 321 |
| **Study co-coordinator** | Arti Makwana | Arti.makwana@nhs.net | 07584 361 570 |
| **KMPT R&D contact** | Reuben Fakoya | Reuben.fakoya@nhs.net | 07867 138 350 |

**What if there is a problem?**

The Sponsor, Kent & Medway NHS & Social Care Partnership Trust (KMPT) has indemnity and insurance arrangements in place through the NHS Indemnity Scheme to cover legal liability that may arise from fault in the management, design or conduct of the research. Participating NHS sites have indemnity and insurance in place through this scheme to cover legal liability that may arise from fault in the local conduct of the research. In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

If you have a concern or complaint about the study, please speak to the researchers using the contact details below:

**Perinatal Mental Health Multimedia Campaign,**

Research and Development Offices,

Beech House,

Hermitage Lane,

Maidstone,

ME16 9PH

**Telephone:** 07584 361 570 or 07867 138 350

**Email:** [KMPT.Research@nhs.net](mailto:KMPT.Research@nhs.net)

**Sources of further support**

If you require further support concerning your mental health and wellbeing please contact your general practitioner (GP), Midwife, Health Visitor, your local care team or the sources of support below:

|  |  |
| --- | --- |
| **Service** | **Contact details** |
| **Samaritans**  Confidential emotional support for those in distress | Helpline: 116 123  Email: [jo@samaritans.org](mailto:jo@samaritans.org)  Website: [www.samaritans.org](http://www.samaritans.org) |
| **Association of post-natal illness**  An informative website and forum run by those who have/are experiencing post-natal illness. | Website: [www.pni.org.uk](http://www.pni.org.uk)  Helpline: 0207 386 0868 (10am-2pm)  Email: info@apni.org |
| **Mind**  Advice and support for anyone experiencing a mental health problem | Website: [www.mind.org.uk](http://www.mind.org.uk)  Twitter: @mindcharity  Facebook: @mindforbettermentalhealth |
| **Tommy’s**  Tommy’s has a team of in-house midwives who offer free support and information for women and their families at any stage of pregnancy and after the birth. | Website: [www.tommys.org](http://www.tommys.org/)  Helpline: 0800 0147 800 (Monday-Friday, 9am-5pm)  Email: [midwife@tommys.org](mailto:midwife@tommys.org) |

**What to do next?**

If you are interested in taking part, please read through the online consent form carefully and if you are happy to give your informed consent, access to the survey will then be granted.

**Thank you for reading this information sheet and for considering taking part.**