Information Sheet: sharing your routinely collected data

One page summary

We are doing some research to help us understand how local services run by voluntary or charitable organisations can best support the wellbeing of young mothers and birthing parents during the perinatal period (this is during pregnancy and one year after birth). The service you attend is taking part.

We would like to understand who attends this service and why. To do this, we would like to look at the information that is collected and recorded about parents under 25 who receive support. This will help us understand how many mothers and birthing parents are referred to and use the service. It will also help us to understand their demographics. Demographic information describes things such as age, ethnicity or sexuality. We'd also like to know about neurodiversity, disabilities, health issues, and other services you receive. We might also look at other information that the service collects, such as changes to your wellbeing or mental health.

To help us do this, we are asking young mothers and birthing parents who use the service for their permission for the service to provide this information anonymously to the researchers working on the project (Ruth Naughton-Doe or Beth Casey). All your information will be anonymised when we receive it, which means we will not know your name or any contact details.

We will use anonymous information about young parents who are supported by the service to learn about who uses and benefit from these services, and find out if there are barriers for some groups. We'll use this knowledge to help improve support for young parents. You do not have to give permission to share your information if you don't want to.

We want our study to be as inclusive and accessible as possible for people with different needs, experiences, disabilities and backgrounds.

If you want to find out more about the research, please read on. Beth and Ruth are based at the University of York and their details are at the end.

You can also read a bit more about the research on the website: www.perinatalsupport.co.uk

Full Information Sheet

What is this research about?

We know that parents of any age can experience mental health problems, but we are interested in the experiences of parents aged under 25.

We are doing some research to help understand how local services provided by charitable or voluntary organisations can best support younger mothers and birthing parents' mental wellbeing during the perinatal period (this is during pregnancy and one year after birth).

As part of this research, we would like to understand who attends the service and why.

Who is carrying out the research?

This research team includes researchers from the University of York and the University of Oxford, maternal and perinatal mental health service professionals, and women with experience of being a young mother.

Why have I been invited to take part?

You have been invited to take part because you receive support from a service that is involved in our research.

To help us understand how the service works, we would like to look at the information that is collected and recorded about people who receive support. This will include finding out how many parents are referred to the service and their demographics. This means information including age and ethnicity. We are also interested in whether people who use the service have health issues, disabilities or neurodiversity.

We might also look at other information that is collected, for example, about any changes to wellbeing or mental health. It might also be useful to find out if parents are referred to any other services for support.

What will happen if I decide to take part?

If you decide that you would like to take part, the service will send the research team anonymised information that is collected about you. We will not know your name or any contact information. The two researchers Dr Ruth Naughton-Doe and Dr Beth Casey will then use anonymous information about people who are supported by the service to try to understand who is using the service and with what benefits.

Do I have to take part?

No. It is up to you. If you did choose to take part, you can change your mind without giving a reason. Whether or not you choose to take part, will have no impact on the services or support that you receive now or in the future. You could also ask for your information not to be used in the research up to two weeks after it has been collected by contacting Ruth or Beth, the researchers (see below for contact details).

What are the benefits of taking part?

We think it is important that we look at this information to help us to understand how the service works, who is benefiting and what could be improved. This might not help you personally, but it may help others in the future.

Will anyone else know that I am taking part in the research?

If you give permission, information collected about you by the service will be shared anonymously with the researchers working on the project (Ruth and Beth). The anonymised data will be saved on the University of York secure file server (see GDPR information below for further details).

What happens at the end of the research?

We will include summaries of this information when we write up the research. For example, we might report that 30 young people attend the service and then include a breakdown of their ages and ethnicities.

Who has reviewed the research?

The research has been approved by the School of Business and Society Research Ethics Committee at the University of York.

What do I need to do next?

If you decide that you would like to take part in the research, please complete the consent form with the staff member. They will then pass this on to the researchers.

If you are under 16 we will need to ask your parent, carer or an appropriate adult if it is OK for you to take part. They will also need to complete a Consent Form for Parents and Carers. With your permission, we can send information about the study to your parent/carer/appropriate adult. If you want, you can have a chat about the study and your decision to take part with them. This is up to you.

If you have any questions, you can ask your support worker, or you can contact Beth Casey or Ruth Naughton-Doe at the University of York on 07385 955608 (call, text or WhatsApp) or email: sw-perinatal-research@york.ac.uk

What can I do if I have any concerns about the study?

If you have any concerns about the study you can contact Professor Martin Webber (martin.webber@york.ac.uk) at the University of York in the first instance.

Thank you for finding the time to read this information sheet.

Data Information sheet

The purpose of this data information sheet is to explain how your data will be used and protected, in line with the General Data Protection Regulation (GDPR).

On what basis will you process my data?

Under the GDPR, the University must identify a legal basis for processing personal data and, where appropriate, an additional condition for processing special category data. In line with our charter which states that we advance learning and knowledge by teaching and research, the University processes personal data for research purposes under Article 6 (1) (e) of the GDPR:

Processing is necessary for the performance of a task carried out in the public interest.

Special category data is processed under Article 9 (2) (j):

Processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes

Research will only be undertaken where ethical approval has been obtained, where there is a clear public interest and where appropriate safeguards have been put in place to protect data. In line with ethical expectations and to comply with common law duty of confidentiality, we will seek your consent to participate where appropriate. The legal basis for processing your data will be the GDPR.

How will you use my data?

Data will be processed for the purposes outlined in this notice and in the main information sheet. All conversations, interviews and focus groups will be audio-recorded (with consent). The device used for audio-recording will be password protected; the audio file will be transferred to the secure password-protected University of York fileserver at the earliest opportunity and then deleted from the recording device. The audio-recording of the conversations, interviews and focus groups will be transcribed and anonymised by the researcher. Anonymised findings will be analysed and used to evaluate the community-based research sites providing support for young mothers. A research paper and other outputs will be prepared for submission to an academic journal.

How will you keep my data secure?

The University will put in place appropriate technical and organisational measures to protect your personal data and/or special category data. For the purposes of this project we will ensure that all audio files and transcripts are password protected and saved onto the secure University of York fileserver. Information will be treated confidentiality and shared on a need-to-know basis only. The University is committed to the principle of data protection by design and default and will collect the minimum amount of data necessary for the project.

Will you share my data with third parties?

Data will only be accessible to the research team at the University of York; only the anonymised findings will be shared with others. We will request that other researchers have access to the anonymised transcripts for future research, but you will have the opportunity to opt out of this at the consent stage.

Will I be identified in any research outputs?

You will not be identified in any research output. Names or other potentially identifying information will not be used. Consent will be required for us to use direct quotes in publications, but these will be untraceable back to participants. Participants do not have to consent to this.

How long will you keep my data?

Data will be retained in line with legal requirements or where there is a business need. Retention timeframes will be determined in line with the University's Records Retention Schedule. Anonymised transcripts (with all personal names removed) will be kept for ten years from the end of the study; electronic copies of consent forms and audio recordings of consent will be kept for three years from the end of the study; audio recordings of the interviews will be securely destroyed at the end of the study.

What rights do I have in relation to my data?

Under the GDPR, you have a general right of access to your data, a right to correction, erasure, restriction, objection or portability. You also have a right to withdrawal. Please note, not all rights apply where data is processed purely for research purposes. For further information see:

https://www.york.ac.uk/records-management/generaldataprotectionregulation/individualsrights/.

For this particular study, you have the right to withdraw your data up to two weeks after your interview has taken place.

Questions

If you have any questions about this participant information sheet or concerns about how your data is being processed, please contact the study researchers Dr Beth Casey and Ruth Naughton-Doe at the University of York in the first instance (sw-perinatal-research@york.ac.uk). If you are still dissatisfied, please contact the University's Data Protection Officer at dataprotection@york.ac.uk.

If you are unhappy with the way in which the University has handled your personal data, you have a right to complain to the Information Commissioner's Office. For information on reporting a concern to the Information Commissioner's Office, see www.ico.org.uk/concerns.