

The Convene Study Understanding Conversations to Improve Training for Midwives

Information for midwives

Invitation to take part in a research study

We are inviting you to take part in a research study. Joining the study is entirely up to you. Before you decide, it is important to know why the research is being done and what it will involve. You will be asked in confidence whether you wish to take part, and the research team will not share details of those participating.

What is the research about?

Midwives want to be certain they are giving all women the information they needed to help decide whether or not to have antenatal screening tests for Down's syndrome, Edward's syndrome and Patau's syndrome's. Research shows that NHS midwives do their best to support all women with their screening decision, whilst working within significant time constraints.

We want to record antenatal booking appointments to help us to understand how midwives and women talk about antenatal screening tests 'in real life'. The recordings will be studied by researchers to find out what different women want and how midwives can help them. Small sections of anonymised recordings (faces and voices disguised) may be used in the future training of midwives.

This research could help to improve the training midwives receive around offering this information. The study will focus on the way conversations are generated, rather than exploring the specific screening information given to women.



An example of how the videos will look when used in training for midwives. Faces and voices are disquised.



The research is funded by the charity Wellbeing of Women and is being run by the University of Leeds in collaboration with Leeds Teaching Hospitals Trust and Loughborough University.

All midwives taking part in this research will be invited to a workshop in January 2020 at the University of Leeds, where the findings will be shared with them and with representatives of Public Health England and NHS staff responsible for delivering training on antenatal screening to midwives.

Why have I been invited to participate?

Between June and August 2019 we are asking pregnant women in Leeds attending their booking appointment - and their midwives - if they would like to help with this research. We would like to video and audio record booking appointments, to capture conversations around antenatal screening.

The recordings will be analysed to help us to understand how midwives and women talk 'in real life'. This study could lead to training that offers midwives skills in tailoring discussions to meet individual needs in a busy clinical setting. Small sections of some anonymised (faces/voices disguised) recordings may be used in in training for midwives and researchers, but this is optional.

What will I have to do?

The appointment will run as usual, the researcher will obtain consent from all taking part, and will oversee the recording equipment. They will switch on the recording equipment at the start of the appointment then immediately leave the room and remain outside until it has ended. We understand that some may feel apprehensive or uncertain around being video recorded whilst at work, and audio only recording is also option if preferred. We will also ask for some brief details, including an insight into your professional background.

Who needs to give their permission to be recorded during the appointment?

All adults at the appointment will be asked for permission to be recorded - including women, interpreters, partners and all invited to come. The researcher will discuss the study with women and partners on their arrival, and obtain their consent if they agree. Recording will not go ahead unless everyone agrees, and everyone can choose to stop the recording at any time during or after the appointment, and withdraw from the study.



Will the appointment be different if I take part?

The appointment will run exactly the same as it normally would, and the researcher will be available to answer any questions before, during and after the recording. The video camera will not be noticeable - it's around the size of a large orange, and will be on a stand in the corner of the room. We will also use a small audio recorder (around the size of a mobile phone), to ensure we capture the appointment if the video equipment develops a fault.

What if I have concerns about the information discussed - for example if a sensitive issue is raised?

You can ask to withdraw from the study at any time, please speak to the researcher if you have any concerns.

How will my recordings be used and stored?

Your identifiable recording will be stored securely at the University of Leeds, and a copy sent securely to Loughborough University, where the recorded conversations will be stored securely and analysed. This secure storage of the original recordings will continue until the study is complete in January 2020, then they will be destroyed. Those giving permission for use of recordings in staff training may have sections from their anonymised recording shown in training workshops for midwives, health professionals and other researchers. All anonymous recordings will be stored securely at both the University of Leeds and Loughborough University for 25 years, in accordance with national data protection guidance. Extracts from these anonymised recordings may be used in research reports and publications.

If you would like a summary of the study findings, please contact Jayne Wagstaff on 0113 2066473 between 31/1/20 - 29/2/20.

Who should I Contact if I wish to make a complaint?

Leeds Teaching Hospitals Patient Advice and Liaison Service (PALS) and Complaints: Please contact the PALS team

Tel: (0113) 2066261 - Available during normal working hours only (9:00am to 4:30pm Monday to Friday).

Tel: (0113) 2067168 - For queries outside of normal working hours, please leave a voicemail.

E mail: patientexperience.leedsth@nhs.net

Or Clare E.Skinner, Head of Research Integrity and Governance, University of Leeds.

Tel: (0113) 343 4897

Email: governance-ethics@leeds.ac.uk



What will happen to any data I give?

The University of Leeds is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Leeds will keep identifiable information (recordings) about you until the study has finished in January 2020. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will remove the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information at:

https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-

Privacy-Notice.pdf. Leeds Teaching Hospitals Trust will keep your name confidential and will not pass this information to the University of Leeds. Leeds Teaching Hospitals Trust will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded, and to oversee the quality of the study. Certain individuals from the University of Leeds and regulatory organisations may look at your research records to check the accuracy of the research study. The University of Leeds will receive identifiable information (recordings). The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. Leeds Teaching Hospitals will keep identifiable information (consent form), and the University of Leeds and Loughborough University will store analysed data (sections of anonymised recordings) from this study for 25 years after the study has finished. When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research. This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you. It will not be used to make decisions about future services available to you, such as insurance.

Thank you for considering this invitation to take part in our research. Please contact Jayne Wagstaff (Research midwife) on 07768 278451 or Louise Bryant (Associate Professor in Medical Psychology) on 0113 343 1882 if you would like further information.

