



The Convene Study Understanding Conversations to Improve Training for Midwives

Information for women attending the booking appointment

Would you like to take part in our research?

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. Please read this information carefully, and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you want to take part.

What is the research about?

At the first appointment a women has with her midwife (called the booking appointment) women are offered antenatal screening tests for Down's syndrome, Edwards' syndrome, and Patau's syndrome. Midwives want to be sure that they are giving women the information they need to help them make the right decision for them.

This study aims to improve the training midwives are given so that they can better help women make screening decisions. We want to record antenatal booking appointments to help us to understand how midwives and women talk about antenatal screening tests 'in real life'. We think women want to talk about screening tests in different ways and some want more, or different, information than others. 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 picture is an example of how the videos will look when used in training for midwives. Faces and voices are disguised.

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.



Why have I been invited to join the research?

Between June and August 2019 we are asking pregnant women in Leeds attending their first midwife appointment if they would like to help with this research.

What usually happens during the booking appointment?

You will meet your midwife, discuss your general health, and have your height, weight and blood pressure measured, along with a urine sample tested for protein and glucose. You will not be asked to undress during the appointment.

You will receive pregnancy health advice, and information about antenatal screening tests for Down's syndrome, Edward's syndrome, and Patau's syndrome.

What will I have to do if I take part in the study?

You will attend your appointment as normal, and it will run as it usually would.

A video camera around the size of a large orange will be on a stand in the corner of the room and will not be very noticeable. We will also use a small audio recorder (around the size of a mobile phone), to record the conversation in case the camera develops a fault. Everyone in the room will be reminded that they can choose to stop the recording at any time. You can say you don't want your recording to be part of the study if you change your mind. The researcher 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 people may feel uncertain or self-conscious about being videoed. If you would prefer not to be videoed but are happy for your voice to be recorded you can choose to do this. If you would rather not take part at all this is absolutely fine.

If you agree to take part, you will be asked to sign a consent form before the appointment so we know you have received and understood this information. Some of the recordings may also be used in future studies or for training researchers. You can choose whether or not you agree for anonymised recordings to be used in training for midwives or other researchers. We will also ask you for some brief details including your age and your GP's postcode.

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 midwives, interpreters, partners and anyone you invite to come along with you. Recording will not go ahead unless everyone agrees, and permission can be withdrawn at any time during or after the appointment without giving a reason.



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

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

How will my recordings be used and stored?

Your 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, and then 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 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.

Are there any benefits in taking part?

There are no direct benefits to you in taking part. The study aims to inform training for midwives and could improve the experience of women in the future.

Are there any disadvantages or risks in taking part?

There are no disadvantages or obvious risks to taking part. The research team will ensure that your thoughts and feelings are respected at all times.

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 provide? 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 only receive information without any identifying information. 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 or to affect your care. 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.**

