



Empath

Patient Information Leaflet (Parent / Guardian)

IRAS Project ID:	327106
Title of Study:	EMPatH: Exa Mining the Experiences of Trans gender Patients and their Healthcare Professionals at Milton Keynes University H ospital
Chief Investigator:	Dr Julia Petty
Principal Investigator:	Thandiwe Rosemarysdóttir (This study is part of a PhD student research project.)

What is the Empath study? The aim of this study is to explore your child's feelings and emotions during their hospital visit. We will compare this with how the nurse, doctor, or healthcare assistant looking after your child felt at the same visit. This member of staff will be chosen by your child. Your child will take part in a single one-to-one interview with the researcher. They will use photographs to represent their feelings and emotions about their hospital visit. This is so that we can understand what is happening when patients and staff have good experiences of healthcare. Then we can make sure that those conditions are in place at every visit.

Study duration Your child will only have one interview. It is not expected to last longer than 1 1/2 hours.

How will we use information about your child?

In this research study we will use information from your child and their medical records. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study. Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

At the end of the study we will save some of the data in case we need to check it. We will make sure no-one can work out who you are from the reports we write.

The full information sheet tells you more about this.

If you and your child are interested in your child taking part, please read the rest of the information sheet.



Participant Information Sheet

We would like to invite your child to take part in our research study. Before you decide we want you to understand why the research is being done and what your child would need to do. One of our team will go through the information sheet with you and your child. There is an information sheet for your child to read too. They will answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

Transgender people can have traumatic experiences of healthcare. This may be because of stigma, lack of knowledge or experience in their healthcare professional, or hospital systems that are not inclusive. Healthcare professionals can experience difficulties delivering care to transgender patients for the same reasons. This study will explore the two points of view of the same hospital visit. It will try to understand what contributes to a good experience of care and caregiving. The study will be undertaken as part of a PhD.

Why has my child been invited?

Your child has said that their gender is different from the one they were assigned at birth.

Does my child have to take part?

It is up to you and your child to decide if they want to take part. They do not have to take part, and there are no negative consequences if they decide not to. If they do decide to take part, you will be given this information sheet to keep. You will be asked to sign a consent form. Your child will be asked to sign an assent form. You are both always free to withdraw at any time. You do not need to give a reason. This will not affect your, or your child's, legal rights.

What will happen to my child if they take part?

If you and your child decide to take part, we will arrange an interview with your child. This will be face-to-face, somewhere they feel comfortable and safe. This may be at the hospital, or it may be at the Milton Keynes Library in a quiet room. The interview will last no more than 1 1/2 hours. It will explore their feelings and emotions during their hospital visit, and what made them feel that way. Once the consent and assent forms have been signed we will contact your child directly via email or mobile phone.



There are no follow-up visits.

Expenses and payments

Participants will not be paid to take part in the study.

What are the possible benefits of taking part?

We can't promise the study will help your child. The information we get from this study may help to support transgender and non-binary children, and staff in hospital in the future.

What are the possible disadvantages of taking part?

The interview will take up some of your time. If your child felt upset or distressed about their care, this may come up again during the interview. If your child feels they need more support after the interview, the researchers will signpost you to people who can give them support.

What happens when the research study stops?

At the end of the study the results will be analysed. They will be put together into a report. A copy of this report can be sent to you and your child if you consent to us holding your contact details for this purpose.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If your child is a patient and you or they remain unhappy and wish to complain formally, you can do this by contacting the Patient and Advice Liaison Service at MKUH on 01908 995954.

If something goes wrong and your child is harmed by the research, and this was due to someone's negligence then you may be able to take legal action to get compensation from the University of Hertfordshire. You may have to pay your legal costs.

The normal NHS complaints processes will be available to you.



How will we use information about you?

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At the end of the study we will save some of the data in case we need to check it. We will make sure no-one can work out who you are from the reports we write. This information will include your name 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.

The University of Hertfordshire is the sponsor of this research, and is responsible for looking after your child's information. We will share your information related to this research project with the University of Hertfordshire research team for this study.

We will keep all information about your child safe and secure by:

- using a code to identify them
- keeping their information including their assent form, your consent form, their interview recording, and their interview transcript in a locked cupboard that only the researcher can access
- electronic records will be held on a password-protected secure server

How will we use your information when the study ends?

Once we have finished the study, we will keep some of the data 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.

We will keep your study data for a maximum of **five** years. The study data will then be fully anonymised and securely archived or destroyed. Audio files will be stored for three months after completion of the study and then will be securely destroyed.

What are your choices about how your information is used?

- you can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.



- you have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

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

You can find out more about how we use your information by contacting the research team at the end of this information sheet.

Although what you and your child say to us is confidential, if you or your child disclose anything to us which we feel puts your child or anyone else at any risk, we may feel it necessary to report this to the appropriate people.

Who is organising and funding the research?

The research is being organised by the University of Hertfordshire. They are the Sponsor. Milton Keynes University Hospital NHS Foundation Trust is funding the research.

Who has reviewed the study?

All research in healthcare is looked at by a Research Ethics Committee. This is an independent group of people whose job is to protect your, and your child's interests. This study has been reviewed and given a favourable opinion by the Camden and King's Cross NHS Research Ethics Committee.

Further information and contact details

Study coordinator / Principal Investigator

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