



Empath

Patient Information Leaflet (Adolescent Patient)

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

What is the Empath Study? This study will explore the feelings and emotions you had during your hospital visit. We will compare this with how the nurse, doctor, or healthcare assistant looking after you felt at the same visit. This member of staff will be chosen by you. If you join the study, you will have a single one-to-one interview with the researcher. You will use photographs and word cards to represent your feelings and emotions about your 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 You will only have one interview. It is not expected to last longer than 2 hours.

Data Security For this study we will use the information you give us, and your hospital records. We will only use the information that we need for the study. We will share your name and contact details with as few people as possible. We will only share this if they need them for this study. Everyone involved in this study will keep your data safe and secure. We will 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 in the reports we write.

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



Participant Information Sheet

We would like to invite you to take part in our research study. Before you decide we want you to understand why the research is being done and what you would need to do. One of our team will go through the information sheet with you. 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 have I been invited?

You have said that you identify your gender as different from the one you were assigned at birth.

Do I have to take part?

It is up to you to decide whether you take part. It is up to you to decide whether you take part. You do not have to take part, and there are no negative consequences if you decide not to. If you decide to take part, you will be given this information sheet to keep. Because you are legally a minor, you will be asked to sign an assent form. Your parent or guardian will be asked to sign a consent form so you can take part. If you decide to take part, you are always free to withdraw at any time. You do not have to give a reason. This will not affect your legal rights.



What will happen to me if I take part?

If you decide to take part, then we will arrange an interview with you. This will be face to face, somewhere you feel comfortable and safe. This may be at the hospital, or it may be at Milton Keynes Library in a quiet room. The interview will last no more than 2 hours. It will explore how you felt during your hospital visit, and what made you feel that way.

Follow up visits

There are no follow-up visits.

Expenses and payments

You will not be paid to participate in the study.

What are the possible benefits of taking part?

We cannot promise the study will help you. The information we get from this study may help to support young transgender and gender-diverse people in hospital in the future.

What are the possible disadvantages and risks of taking part?

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

What happens when the research study stops?

At the end of the study the results will be analysed and put together into a report. A copy of this report will be sent to you if you agree that we can keep your personal information for this purpose.

What if there is a problem?

If you are worried about any part of this study, you should ask to speak to the researchers. They will do their best to answer your questions. The researchers' contact



details are given at the end of this information sheet. If you are a patient and 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 you are harmed during the research, and this is due to someone's negligence then you may have grounds for legal action for compensation against the University of Hertfordshire. You may have to pay your legal costs.

The normal NHS complaints processes will be available to you.

Will my taking part in the study be kept confidential?

We will follow ethical and legal rules. All information about you will be handled in confidence.

If you join the study, we will use information collected from you during the research. This information will be kept strictly confidential, stored in a secure and locked office. It will be kept on a password-protected database at the University of Hertfordshire. Under UK Data Protection laws, the University is the Data Controller (legally responsible for the data security). The Principal Investigator of this study, Thandiwe Rosemarysdóttir, is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited. We need to manage your information in specific ways to comply with the law, and for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information and read our privacy notice [at:](#)

The data collected for the study will be looked at and stored by authorised people from the University of Hertfordshire. The data may also be looked at by authorised



people from regulatory organisations. They will check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant. We will do our best to meet this duty.

Where possible, information about you that leaves the hospital will have your name and address removed. They will be replaced with a unique code so that you cannot be recognised from it. This personal data will be looked at and stored for these purposes by authorised people from Milton Keynes University Hospital.

Your contact information will be kept by the University of Hertfordshire for 3 months after the end of the study. This is so that we can contact you about the findings of the study, unless you tell us that you do not wish to be contacted. This information will be kept separately from the research data collected. Only those who need to will have access to it. All other research data will be kept securely for 5 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality. Only members of the research team permitted by the data custodian will have access to your data.

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

What will happen if I don't want to carry on with the study?

Taking part is voluntary, and you are free to withdraw at any time. You do not have to give a reason. Your legal rights will not be affected. If you withdraw, we will stop collecting your information. We will keep the information about you that we have already gathered. This information may have already been used in some analyses. It may still be used in the final study analyses. To protect your identity and rights, we will use the minimum personally identifiable information possible.



Who is organising and funding the research?

This research is being organised by the University of Hertfordshire. They are the sponsor for this research. Milton Keynes University Hospital NHS Foundation Trust is funding this research.

Who has reviewed the study?

All healthcare research is looked at by a Research Ethics Committee. This is an independent group of people whose job is to protect your interests. This study has been reviewed and given a favourable opinion by the xxx NHS Research Ethics Committee.

Further information and contact details

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