# Empath

## Patient Information Sheet (Adult Patient)

| | |
|---|---|
| **IRAS Project ID:** | 327106 |
| **Title of Study:** | EMPatH: **E**xa**M**ining the Experiences of **T**ransgender Patients **a**nd **t**heir Healthcare Professionals at Milton Keynes University **H**ospital |
| **Chief Investigator:** | Dr Julia Petty |
| **Principle Investigator:** | Thandiwe Rosemarysdóttir<br>(This study is part of a PhD student research project.) |

**What is the Empath Study?** This study aims to explore how you experienced your hospital visit. This will be compared with how the nurse, doctor, or healthcare assistant looking after you experienced the same visit. This member of staff will be chosen by you. You will take part in a single one-to-one interview with the researcher. You will use photographs 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 1 1/2 hours.

**How will we use information about you?**

In this research study we will use information from you and your 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 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 your gender is 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. 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. You will be asked to sign a consent form.  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 1 1/2 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 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 consent for us to holding your contact details 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 does go 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 mechanisms will be available to you.

**How will we use information about you?**

In this research study we will use information from you and your 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. 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 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 you safe and secure by:

- using a code to identify you
- keeping your information including your consent form, your interview recording, and your 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.

***What you say to us is confidential, but 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.***

**Who is organising and funding the research?** This research is being organised by the University of Hertfordshire. They are the sponsor. 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 Camden and King's Cross NHS Research Ethics Committee.

**Further information and contact details**

***Study coordinator / Principal Investigator***
Thandiwe Rosemarysdóttir
PhD Student and Research Nurse
The University of Hertfordshire
ar21aat@herts.ac.uk
Work phone: xxx (Mon-Fri)

***Chief investigator***
Dr Julia Petty
The University of Hertfordshire
j.petty@herts.ac.uk
Work phone xxx (Mon-Fri)