

**Health inequalities & tackling antimicrobial resistance in sexual health**

**A study of antibiotic treatment and experiences of bacterial infection**

**Name of Researchers: Dr Catherine Will & Dr Ulla McKnight, University of Sussex.**

**Summary of the study:**

You are invited to take part in a research study. The study is sponsored by the University of Sussex and funded by the Wellcome Trust.

The research aims to better understand how patients and health care practitioners' talk about antibiotics and treat bacterial infections in different clinics and how both groups feel about care, medicines and infections. This is important because health care is facing more infections that are resistant to the antibiotics we have at the moment. The researchers will use the information they collect to help health care practitioners meet their patients' needs.

A researcher would like to sit in on your next appointment in the clinic and observe what is said and done. The researcher will focus on watching the things your health care practitioner says and does. The researcher will write notes about the things she observes. This information will be used to propose better ways to talk about and treat bacterial infections. The researcher will leave the room if you have a physical examination.

You might also be invited to be interviewed by a researcher. The researcher would like to have a conversation with you about your experiences in the clinic, your feelings about medical care, infections and treatment. The interviews will be used to help the researchers understand these issues from a patient's point of view. If you agree to be interviewed, you will be given a voucher as compensation for your time.

In this research study we will use information from you. We will only use information that we need for the research study. If you agree to an interview, we will let very few people know your name, 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 information pack tells you more about this.

## Why are we doing the study?

Some of the antibiotics that are currently used to tackle infections are not working very well. So, healthcare providers and policy makers need to think carefully about how antibiotics are prescribed to patients. This study aims to help health care practitioners and policy makers better understand how to care for, prescribe and talk about antibiotics and bacterial infections to different patients.

We think the best way to do this is to talk to patients and their health care practitioners about their experiences, thoughts and feelings. That is why we are interviewing patients and practitioners. We also think it is important to find out how bacterial infections and antibiotics are talked about and treated in this clinic. This information will help us better understand how clinics manage these issues – and what difficulties they face in practice. That's why the researchers would like to sit in on medical consultations.

All research in the NHS is reviewed by an independent group of people, called a Research Ethics Committee, which is there to protect your safety, rights, wellbeing and dignity. This project has been reviewed and was given a favourable review by the London - Brighton and Sussex NHS Research Ethics Committee, and the University of Sussex Sponsorship Sub-Committee (SSC), as well as by experts in social science, a lay review panel and patient representatives. We cannot promise that this study will help you, but it might help clinics and policy makers better understand how they can improve care.

## Why am I being asked to take part?

You have been invited to take part in this study because you have an appointment at one of the clinics that is involved with this project. You don't have to agree. It is up to you to decide whether or not you wish to take part. In this information pack we will describe what would happen if you do. We are ready to answer any questions you might have before you decide.

## What will I need to do if I take part?

If you choose to do so there are two ways of taking part:

- i) Agreeing to an observation in your next appointment

The researcher would like to observe your appointment in the clinic. This means that the researcher would sit in the room while you have your appointment. She would pay attention to and write down what your care provider says and does during the appointment. She might also ask a few questions about what is being done. The researcher will leave the room if you have a physical examination. The researcher will not record your name or any information

that could identify you. If you are happy for the researcher to sit in on your appointment, please tell a member of your healthcare team and they will introduce you to the researcher.

ii) Being interviewed

You may also be invited to be interviewed by the researcher. The researcher would like to talk with patients about their experiences of sexual health and health care. The interview will last for about one hour and will be similar to a conversation between you and the researcher. **During the interview the researcher may ask questions about your experiences in the clinic, your life and your background. You do not have to answer any questions you would prefer not to.** The researcher would like to record the interview – but she can take notes if you would prefer. We would like to publish anonymous quotations from interviews.

If you are happy to be interviewed, you and the researcher will pick a time and private safe place (usually within the clinic – but she can arrange a room elsewhere if you prefer). Before the interview, the researcher will read this pack with you and answer any questions you might have. If you are happy to go ahead with the interview proceed, she will ask you to sign a consent form. You will be given a copy of the consent form. Please text or phone Dr Ulla McKnight if you might like to be interviewed.

In exceptional circumstances and in line with Trust policy we will be required to pass any concerns onto safeguarding staff at the clinic if we are worried that your safety or the safety of others seems at risk.

**More information about taking part**

**Compensation**

**If you agree to be interviewed, you will be compensated for your time with a voucher worth £20 per interview.**

**Possible disadvantages**

It is possible that having an observer in your consultation and/or talking about issues relating to infections could be upsetting and could cause some embarrassment or raise questions. You will be able to talk to a trained member of staff if you become upset or have any questions that the researcher is not able to answer. The researcher will give you information about support groups if you wish. If you have any complaints about the study contact us or Dr Antony Walsh, the Research Governance Officer at the University of Sussex. The University has insurance in place to cover its legal liabilities in respect of this study. You can also complain formally through the NHS Patient Advice and Liaison Service (PALS) (see contacts below).

## **What are your choices about how your information is used?**

- You can stop being part of the study at any time up to two months after you have taken part, without giving a reason. If so we will destroy transcripts of interviews with you, but we will need to keep a record of your name, participation and withdrawal.
- We need to manage your records in specific ways for the research to be reliable. This means we are not able to let you see or change the data we hold about you.

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

You can find out more about how we use your information from the Health Research Authority at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/) or the leaflet available from [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch).

You can also ask one of the research team, or contact the University of Sussex Data Protection Officer by sending an email to [dpo@sussex.ac.uk](mailto:dpo@sussex.ac.uk), or by ringing 01273 678472.

## **How we use information about you**

We will need to use information from you for this research project.

If you agree to be interviewed, this information will include your name. 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. Your data will have a code number instead.

We will keep all information about you safe and secure.

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 ensures no-one can work out that you took part in the study.

The information collected for this study will be used to write academic pieces including conference papers and articles, as well as reports and training material for clinical staff and policy makers. All of these will be made available on the project's website where you can sign up for direct updates and news of events. We will also post information about the project on Facebook, Instagram and Twitter [insert addresses].



## How to contact us?

If you have any questions or concerns about any aspect of this study you could talk to the researchers who work on the project – Ulla McKnight or Catherine Will – or to Dr Achyuta Nori or Dr Suneeta Soni who are co-investigators on the research. If you would like to talk to someone outside the project you could contact Antony Walsh, the Research Governance Officer at the University of Sussex. You will also be able to contact the Patient Advice and Liaison Service (PALS) (see contact details below).

Dr Ulla McKnight and Dr Catherine Will  
Freeman Building, School of Law, Politics and Sociology,  
University of Sussex, Falmer, Brighton BN19QE  
Telephone number: 07867138015  
Email address: [u.mcknight@sussex.ac.uk](mailto:u.mcknight@sussex.ac.uk) or  
[c.will@sussex.ac.uk](mailto:c.will@sussex.ac.uk)

Dr Antony Walsh  
Research Governance Officer,  
Falmer House,  
University of Sussex, Falmer, Brighton, BN1 9QF  
Telephone number: +44(0)1273 872748  
Email address: [researchsponsorship@sussex.ac.uk](mailto:researchsponsorship@sussex.ac.uk)

Patient Advice and Liaison Service (PALS)  
Brighton: [01273 696955](tel:01273696955) ext. 64511 or 64973  
[bsuh.pals@nhs.net](mailto:bsuh.pals@nhs.net)  
London: 020 7188 8801  
[pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

**Thank you for  
taking the time to  
read this  
information sheet!**

20<sup>th</sup> December 2019