



Moorfields
World leading experts
in eye care

A British Ophthalmological Surveillance Unit Study (BOSU)
Moorfields Eye Hospital

Adult Gonococcal Eye Infection

What is a gonococcal eye infection?

Gonorrhoea is a sexually transmitted infection (STI) caused by the bacteria *Neisseria gonorrhoeae*. Gonorrhoea usually infects the genitals, rectum or throat but more rarely, it can affect the eyes and cause gonococcal conjunctivitis (GC) or keratoconjunctivitis (GKC). Patients get a red, painful eye with lots of discharge and swollen eyelids. GC and GKC occur from direct contact with infected bodily fluids. The treatment is with antibiotics. If left untreated, gonococcal eye infections can be sight threatening.

In England, the number of people with gonorrhoea increased by 50% between 2021 and 2022; the highest number since records began. With more gonorrhoea occurring, there may be more eye infections.

What are the aims of this study?

This study aims to find out how many adults in the United Kingdom (UK) have gonococcal eye disease. We want to know what the risk factors are, how best it is managed, if the antibiotic treatment works, or if the gonorrhoea is becoming resistant to antibiotics. It will increase our understanding of the condition to improve guidelines for the future.

Where is this study happening?

The study will be taking place in England, Wales, Scotland and Northern Ireland.

How long will the study go on for?

The collection of data will continue for 18 months.

Who is funding this study?

This study is funded by Fight for Sight Bowman Small Grant Award and Moorfields A&E Innovations & Research Unit.

How will the information be collected and stored?

Moorfields Eye Hospital is the Sponsor for this study based in the United Kingdom. We will be using information from your medical records 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. If you are diagnosed with GC/GKC, the doctor who is caring for you will send a limited amount of anonymous information such as the type of symptoms, level of vision, response to treatment to researchers at Moorfields. Your hospital number and part of your date of birth (mm/yyyy) will be kept in a secure database that only the study team will be able to access. People will use this information to do the research or to check your records

to make sure that the research is being done properly. We will keep all information about you safe and secure.

How will collecting the information affect your care?

There will not be any change to, or a negative effect on your care. If your information is used in the study, it will not be possible to identify you, or any other individual. Confidentiality will be maintained at all times.

What are the risks and benefits of taking part in the study?

There are no risks associated with taking part as the study will not influence the care you receive. The benefits of taking part are to help us better understand this sight-threatening eye condition and improve the management guidelines to prevent vision loss.

Can patients choose to not be included in this study?

It is your choice if you want to be included in this study or not. If you do not wish for anonymous information to be used, please inform your eye doctor who will be able to ensure that information on your condition is not included in the research project.

The NHS uses medical records for audits and research to improve future health and care. If you do not wish your medical notes to be used for these purposes, you should let your doctor know. They will be able to record that you do not want your notes used.

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 and we will delete the information about you that we already have. We need to manage your records in specific ways for the research to be reliable.

Data opt out NHS Scotland for Scottish patients:

You have the right to object to your information being used. NHS Scotland will consider your request and respond within 1 calendar month.

Every NHS organisation has a Caldicott Guardian responsible for protecting patient identifiable information. The Caldicott Guardian ensures patient privacy is protected. Please contact your local Caldicott Guardian for further information, or your Data Protection Officer for any data protection concerns.

For further Information on how NHS Scotland may use your personal data for Scottish Patients:

<https://www.nhsinform.scot/care-support-and-rights/health-rights/confidentiality-and-data-protection/how-the-nhs-handles-your-personal-health-information>

<https://www.nss.nhs.scot/how-nss-works/data-protection/>

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

You can find out more about how we use your information:

- at www.hra.nhs.uk/information-about-patients/

- at www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by asking the Data Protection Officer at Moorfields: 020 7253 3411

What is the British Ophthalmological Surveillance Unit (BOSU)?

The BOSU was founded in 1996 by the Royal College of Ophthalmologists. Its aim is to encourage the study of rare eye conditions in the UK.

What does BOSU do?

It allows doctors and researchers to find out how many patients in the UK are affected by a particular disease or condition each year, this is called epidemiological surveillance. Doctors can also gather information about all the cases of a particular rare condition to study what might have caused it, how to diagnose and treat it. Future patients with the condition will benefit from this.

How does BOSU work?

Each month, BOSU sends an email to 1600 specialist eye doctors, which lists the rare conditions currently being studied. If a doctor has seen a patient affected by one of these conditions, they click a link which takes them to a confidential questionnaire asking for more information. BOSU informs the research team about the completed questionnaire. Researchers are not told the names or addresses of patients, and patients or their GP's are not contacted.

What has BOSU achieved?

BOSU has helped to undertake surveys of over 70 rare eye conditions. These have helped to increase understanding of why the conditions occur and aim to provide better diagnoses and treatments.

For further information, concerns or complaints regarding this study please contact:

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Website: <https://www.rcophth.ac.uk/standards-publications-research/audit-and-data/the-british-ophthalmological-surveillance-unit-bosu/>