*A British Ophthalmological Surveillance Unit Surveillance Study*

**Public Information Leaflet**

**Sight Loss due to delay in review or treatment**

This leaflet provides information about a new study of individuals suffering from sight loss caused by delay in review or treatment. It aims to provide information about the how and why this happens, why this study is important and what we hope to show by doing it. It also provides the contact details of the researchers undertaking the study and a link to the website where the results will be published.

**What is Sight Loss due to delay in review or treatment?**

Sight Loss due to delay in review or treatment is very rare but important and can happen when patients are not seen by their doctors or other health care professionals within the desired time period.. Delays in care can occur for a number of reasons. This study is particularly focused on the delays caused by a lack of suitable appointments or capacity within the hospital eye service.

**What are the aims of this study?**

Sight Loss due to delay in review or treatment is avoidable and at present, the exact extent of the frequency is unknown. The study would help to identify number of individuals newly affected in a year and help identify which patients are most at risk so resources can be targeted to help.

**How will the information be collected?**

The doctor who is treating the you will send researchers information about your case, this will be done using a secure online system operated by the Health Informatics Centre at the University of Dundee. The information provided will include your age, gender, ethnicity and postcode, as well as information on the nature of the harm and causes of the delay in review or treatment. Through this information we hope to increase understanding of how frequently this problem occurs across the UK, commonly recurring features. It is hoped that this will contribute to an improvement in reducing delays in the future.

**How will the information be used?**

The study will not have any effect (either negative or positive) on the care and treatment of individuals. Information will not identify any individual and confidentiality will be maintained at all times. It is hoped that collecting information on individuals will help to improve understanding of the problem and its management.

**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 believe that you may be eligible for this study but do not wish for your information to be used please inform your eye doctor who will be able to ensure that information on your care is not included in the research project.

The NHS uses information relating to patients’ health for audit and research purposes and processes this in line with our legal requirements under the General Data Protection Regulations and the Data Protection Act 2018. We have a duty to ensure our process is fair and transparent and patients are aware of how we use their information.

**Where is this study happening?**

The study will be taking place across the United Kingdom.

**How long will the study last?**

The study surveillance will last for 12 months and the data will be kept for 5 years after the study has reported its findings in line with good research practice.

**Who is funding this study?**

This project is supported by The Royal College of Ophthalmologists.

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This project is sponsored by Moorfields Eye Hospital NHS Foundation Trust, London and they will act as the data controller.

**Who to contact if you have any questions about this study**

[Miss](http://aadduk.org/) Rashmi Mathew , Consultant Ophthalmologist, Moorfields Eye Hospital, London

Email: Rashmi.Mathew1@nhs.net

**About** **The British Ophthalmological Surveillance Unit**

**What is the British Ophthalmological Surveillance Unit (BOSU)?**

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

**What does the 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 rare conditions will benefit from this.

**How does the BOSU work?**

Each month the BOSU sends an email to almost 1500 consultant and specialist eye doctors; the card lists the rare conditions currently being studied. If a doctor has seen a patient affected by one of these conditions they inform the research team through a secure online data collection system operated by the Health Infomatics Centre a t the University of Dundee and the provide . information via an online confidential questionnaire. Researchers are not told the names and addresses of patients, and families are not contacted.

**What has the BOSU achieved?**

The BOSU has now helped to undertake surveys of over 80 rare eye conditions. These have helped to increase understanding of why the conditions occur and can help to provide better diagnoses and treatments.

**For further information, contact**

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Information on what NHS Scotland may do with 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>