**What is the British Ophthamological 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 tick a box on the card and send it back. The BOSU informs the research team who send the doctor a confidential questionnaire asking for more information. 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 70 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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**Tel:** 020 7935 0702 **Email:** bosu@rcophth.ac.uk **Website:** <https://www.rcophth.ac.uk/standards-publications-research/audit-and-data/the-british-ophthalmological-surveillance-unit-bosu/>

*BRITISH OPHTHALMOLOGICALSURVEILLANCE UNIT*

*Surveillance Study*

**Public Information Leaflet**

**Sympathetic Ophthalmia**

This leaflet provides information about a new study of individuals suffering from an eye condition called ‘Sympathetic Ophthalmia. It aims to provide information about the condition, 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 Sympathetic Ophthalmia?**

Sympathetic Ophthalmia is a very rare but important and potentially blinding complication of surgery and ocular trauma, with no uniform consensus regarding its optimal management. This condition is a sight-threatening inflammation of the eye that affects the light-seeing part of the eye known as the retina. This condition develops in the healthy fellow that "sympathises" after a period of time following ocular surgery or trauma to the affected and inciting eye.

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

Sympathetic Ophthalmia is a rare but important cause of vision loss in any age group. At present, the exact extent of disease burden is unknown. The study would help to identify number of individuals newly affected by the condition and its treatments.

**How will the information be collected?**

The doctor who is treating the condition will send researchers at BOSU anonymous information about your case. Through this information we hope to increase understanding of this problem and its management.

**How will the information be used?**

The study will not have any negative effect 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 with Sympathetic Ophthalmia will help to improve understanding of the problem and its management.

**Can an individual choose their information not to be used in study?**

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. If you believe that you may be eligible for this study but do not wish for your information to be used please inform your treating clinician who will be able to ensure that information on your condition is not included in the research project.

**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.

**Who is funding this study?**

This project is funded by the British and Eire Vitreoretinal Society and Moorfields Eye Charities.

**Who to contact if you have any questions**

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If you have any concerns about how your data is being used, you can contact the Data Protection Officer at Moorfields Eye Hospital NHS Foundation Trust.