Public Information Leaflet

Posterior Chamber Intraocular Lens (PCIOL) Exchange or Removal After Cataract Surgery

This leaflet provides information about a new study on people who need their artificial eye lenses (PCIOL) replaced or removed after cataract surgery. It explains what the study aims to achieve, why it's important, and how it affects you. It also gives contact details for the researchers and information about where the results will be shared.

What is PCIOL Exchange or Removal?

After cataract surgery, some people need to have their artificial lens (PCIOL) replaced or removed. This can happen for several reasons, such as the lens not being in the right place, becoming cloudy, or causing other problems.

What are the aims of this study?

- To find out how often PCIOL replacement or removal happens in the UK.
- To understand why these procedures are needed and how they are managed.
- To identify how we can reduce the number of PCIOL replacements that happen.

How will the information be collected?

Your doctor will send information about your case, such as your month and year of birth and sex, as well as details about the PCIOL replacement or removal. This helps us understand how often these procedures occur and why, so we can improve care 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. 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 South Tyneside and Sunderland NHS Foundation Trust and they will act as the data controller.

Who to contact if you have any questions about this study

Dr. Mohaimen Al-Zubaidy

Ophthalmologist
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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 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 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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Tel: 020 7935 0702 **Email:** <u>bosu@rcophth.ac.uk</u> **Website:** <u>https://www.rcophth.ac.uk/standards-publications-research/audit-and-data/the-british-ophthalmological-surveillance-unit-bosu/</u>

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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