A British Ophthalmological Surveillance Unit Study (BOSU)

Public Information Leaflet

Chronic Ocular Hypotony

What is it?

Chronic ocular hypotony is a sight-threatening condition. It refers to the pressure inside the eye being low enough for long enough to cause permanent structural changes and vision loss. It is estimated that approximately 100 people in the UK are newly diagnosed with this condition every year. Due to its rarity, there are no robust guidelines to diagnose or treat this disease. We believe it is insufficient to define this condition simply as low pressure resulting in visual loss, as this does not take into account the extent of vision loss, or other forms of visual compromise affecting patients' quality of life such as loss of contrast sensitivity or colour vision.

This study will help shift the focus from defining hypotony in simple numerical terms, to describing the burden of disease in terms of ocular morbidity and long-term visual prognosis. This will provide the most accurate epidemiological data reported to date for this condition. Obtaining and analysing this information has the potential to predict who might be affected most, risk-stratify them, and allow more meaningful and standardised explanations of the possibility of visual loss to patients. Additionally, it will provide the information required for a national framework to help guide correct referral routes for this condition.

What are the aims of this study?

This study aims to find out how many people in the United Kingdom have chronic structural hypotony. We want to know what the risk factors are, how it is diagnosed and managed, and if the treatment works in stabilising or restoring vision (among other outcomes). This will increase our understanding of the condition to improve diagnostic and treatment guidelines for the future.

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, sex, ethnicity, as well as information such as the type of symptoms, level of vision, and the treatment you have received. Through this information we hope to increase understanding of how frequently this condition occurs across the UK and commonly recurring features. It is hoped that this will contribute to an improvement in how doctors manage this condition.

How will collecting the information affect your care?

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 condition and its management.

Can patients choose to not be included in this study?

This research uses anonymous information, which means the research team don’t know whose data it is and can’t ask you. 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 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 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 UK.

How long will the study go on for?

The collection of data will continue for 24 months.

Who is funding this study?

This study is funded by the Research in Eye Disease (RED) Trust, with support from the British Ophthalmological Surveillance Unit (BOSU).

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 2400 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 are not contacted.

What has BOSU achieved?

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

Who to contact if you have any questions or would like to make a complaint?

If you want to complain about how researchers have handled your information, you should contact the research team:

Mr Harry Petrushkin *PhD FRCOphth FFCI FRCP*

Email: h.petrushkin@nhs.net

If you are not happy after that, you can contact the Data Protection Officer:

Mr Jonathan McKee

Email: jonathan.mckee@nhs.net

If you are not happy with either response or believe your data is being processed in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

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

Privacy Policy: The RCOphth Privacy Policy

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