



The ROYAL COLLEGE of  
OPHTHALMOLOGISTS

# BOSU NEWS

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THE SIX MONTHLY BULLETIN OF THE BRITISH OPHTHALMOLOGICAL SURVEILLANCE UNIT

## Dear Colleagues,

Welcome to the first BOSU News for 2018. This year marks our coming of age as we enter our 21st year of rare disease surveillance in the UK. In this issue we have summarised the results of our 20-year evaluation. The most noteworthy of which are the high levels of utilisation of study findings and the non-stop support of the UK ophthalmological community without which the unit would not be able to achieve such success.

Once again, the BOSU will be a prominent feature of the College Congress in May, there will be a stimulating symposium on rare disease epidemiology that will focus on retinal infections, external diseases and paediatric conditions. In addition, 5 studies will present their initial findings and details of these presentations along with references for the six BOSU related papers that have been published since last summer are on the back page.

As usual the newsletter contains progress reports of our current studies. We continue to review new applications, but if you have an idea for a study please do contact the unit to discuss it. We are always keen to hear of new ideas or to revisit past topics.

As always, we are extremely grateful to Fight For Sight for their continued support for the unit.

Details of response rates across the UK are included in this report. We do encourage you to return your card every month indicating any cases of interest you have seen or ticking the 'nothing to report' box, as a high response rate really does improve the quality of the important work undertaken by our researchers.

**Miles Stanford**  
On behalf of the BOSU Steering Committee

## Measuring the Impact of 20 Years of rare eye disease surveillance: The BOSU Evaluation Survey 2017

In 2017 we carried out an evaluation to assess the usefulness, effectiveness, and simplicity of the reporting system, along with the quantity, quality and impact of the research outcomes from studies undertaken through the BOSU.

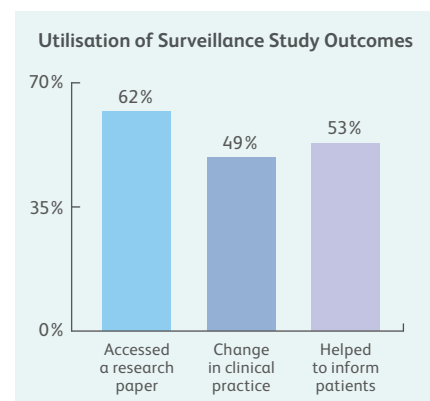
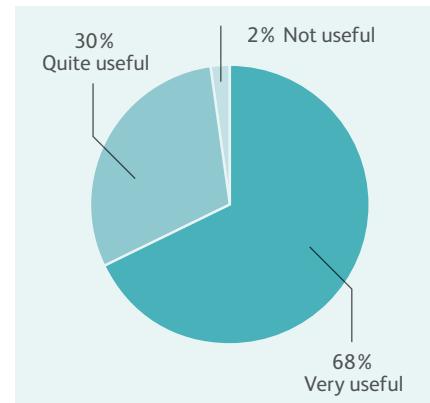
The assessment was undertaken using information from the BOSU database, study publication records and a postal survey of participating ophthalmologists.

Since July 1997 the BOSU has assisted 75 studies leading to 72 peer-reviewed publications and over 120 conference presentations. The unit has been continuously supported by high participation rates from UK ophthalmologists achieving annual card return rates between 70% and 80% since 1999.

The questionnaire survey of participating ophthalmologists sought data on the usefulness of the unit, the ease of participation and the utilisation and influence of study feedback. 946/1418 (67%). questionnaires were returned.

68% considered that the BOSU made a very useful contribution to assisting the research of rare eye diseases, 30% considered the contribution quite useful and only 2% not useful. 82% believed they were receiving an appropriate amount of feedback from research projects both through the BOSU newsletter and conference presentations and peer-review publications. The survey also identified important levels of impact with 62% of respondents having accessed a published paper on a BOSU study, 49% reported changing clinical practice based on the outcomes of a BOSU study and 53% had used the outcomes of a study to help inform patients when obtaining consent.

This evaluation demonstrates the BOSU is effective and sustainable and continues to receive support from UK ophthalmologists, leading to the meaningful publication and utilisation of findings and subsequent practical implementation



THE BOSU IS BASED AT THE ROYAL COLLEGE OF OPHTHALMOLOGISTS

# Ophthalmic Complications associated with Endoscopic Nasal and Sinus Surgery

## Investigators

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I am pleased to report that since the summer this study has certainly picked up momentum with more reported cases and more successfully returned completed questionnaires. Although, two cases were returned as forgotten patient details and so I would like to encourage everyone to

make use of the detachable section of the yellow card to record the patient details ready for when the clinical questionnaire arrives.

50% of reported cases so far were operated on due to nasal blockage and seen in the ophthalmology department within one week. By far the most common reported complication is extraocular muscle trauma with secondary diplopia. Most of these cases seem to be managed medically and resolve with conservative management. Other complications reported include orbital cellulitis, nasal lacrimal duct injury, other soft tissue

injuries and an interesting case of indirect central retinal artery occlusion.

The study is now nearing completion and I am pleased that we extended the reporting by a year. This second year has seen more replies than year one and I am hopeful I will be able to achieve more returns during the final few months. I would like to thank all those who have contributed and encourage everyone to report any cases that they have seen since January 2016 and to return questionnaires in order to ensure as complete reporting as possible.

# The Ophthalmic features of Behçet's Disease in the UK

## Investigators

Mr Harry Petrushkin, Clinical Research Fellow<sup>1</sup>, Miss Sahar Parvizi, Specialist Registrar<sup>1</sup>, Prof Miles Stanford, Professor of Ophthalmology<sup>2</sup>  
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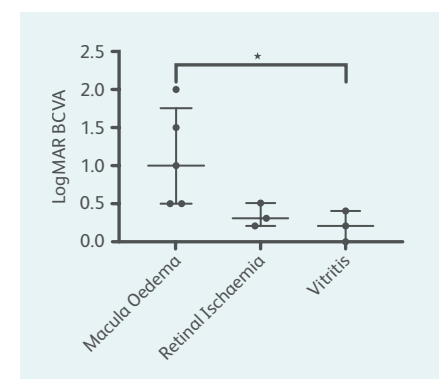
Behçet's Disease is a chronic relapsing-remitting autoinflammatory disease affecting multiple systems, which can result in complete loss of vision in both eyes if untreated. The prevalence of Behçet's Disease varies across the globe and is most frequent along the ancient Silk Road. Despite this, large cohorts of patients have been described in Northern Europe, North America and South America.

The incidence of ophthalmic manifestations of Behçet's Disease across the world is not well documented, varying from 10-80% of cases and there is no data from the UK at present.

Based on data collected so far, the incidence of ophthalmic manifestations of Behçet's Disease is 0.035 per 100,000 individuals per year. The median age of reported cases was 37±11.1yrs (range 15-55yrs). There was no predilection for sex with females making up 52% of cases and males 48%. Fifty per cent of cases had bilateral involvement and 50% unilateral (38% right eye, 12% left eye). The majority of cases were of Northern European ethnicity (72%) followed by Middle Eastern (19%) and North African (9%). The figure below shows the mean the mean ± standard deviation LogMAR best corrected visual acuity (BCVA) for the three most frequently reported ocular manifestations (macula oedema, retinal

ischaemia and vitritis). As can be seen, macula oedema caused significantly more visual morbidity than retinal ischaemia and vitritis.

This study has now been running for over 12 months and the investigators have opted to continue surveillance for another year to increase the confidence of our findings, we would like to thank all colleagues who have reported cases over the past year.



# Birdshot Retinochoroidopathy

## Investigators

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This is the first prospective study of the incidence of Birdshot Retinochoroidopathy

(BSRC). Previous epidemiological studies used to determine incidence and current estimates of BSRC have been based on retrospective data and case series, with the largest series reported prior to the publication of the current diagnostic criteria.

This study started surveillance in May 2017 and will continue for 12 months. In the first 7 months, we have received 19

case reports and it appears that after identifying duplicate and erroneous reports the incidence will be close to our pre-study prediction of around 1-2 reports per month. We are grateful to those who have taken the time to report patients and we look forward to receiving more reports and the completed questionnaires as the study progresses.

## Severe central visual loss (Wipe-out) following cataract surgery

### Investigators

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Wipe-out following cataract surgery has been on the BOSU card for 8 months so far

and as expected, we have been sending out approximately one questionnaire a month, most of which we have had back. Thank you so much to all those who have taken the time to fill in and post back the questionnaires.

As expected, the preliminary data suggests that wipe-out following cataract surgery is related to preexisting glaucoma. In those cases with glaucoma, all have a loss of sensitivity in the central 5 degrees of the

visual field. However, one case reported did not have any history of glaucoma. Of all the cases, only half had high intraocular pressure documented post surgery.

Thank you again to our reporters and please continue to be vigilant and report these rare but important cases to help us collect enough data to make some meaningful conclusions and help guide surgeons plan cataract surgery and counsel patients who may be at risk.

## The Incidence, Presentation, Treatment, and Early Motor Outcomes of Essential Infantile Esotropia in the UK

### Investigators

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1. To determine the incidence of essential infantile/congenital esotropia in the UK.
2. To determine the mean age, race, gender, mode of presentation, the mean angle, and presence of amblyopia pre-surgery.
3. To determine the current clinical practice for the timing of surgical treatment among ophthalmologists in the UK.

4. To determine the early motor outcomes, complications, and presence of amblyopia post-surgery.

We are currently in the early stages of our study that will be running from Oct 2017 to Nov 2018 inclusive. The study will enable us to determine the incidence of essential infantile/congenital esotropia in the UK, along with a description of current clinical practice and an understanding of the early motor outcomes, complications, and presence of amblyopia post-surgery. Information about the study has been disseminated throughout the UK paediatric community via word of mouth, BOSU letters to participating ophthalmologists, email circulation through a paediatric ophthalmology email list, and email circulation through the BIOS (British and Irish Orthoptic Society) email list.

We have currently 11 reports only with 2 replies at the time of writing this report; but will look forward to receiving more as the study progresses. We aim to provide some initial information in the BOSU News.

For interested clinicians, we have a website up and running that can be accessed by typing these words in Google: '**BOSU esotropia**'. The link is [www.welshophth.co.uk/bosu-british-ophthalmic-surveillance-unit-study-on-essential-infantile-esotropia](http://www.welshophth.co.uk/bosu-british-ophthalmic-surveillance-unit-study-on-essential-infantile-esotropia)

From this site, one can access information, receive study updates, read FAQs, and download a PDF leaflet that can be hung up in your paediatric eye clinic.

## New or Worse Sight-Threatening Diabetic Retinopathy in Patients who have had Bariatric Surgery

### Investigators

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This is a new study, having started in November 2017. We are seeking reports of all adult patients with new or worse sight-threatening diabetic retinopathy (pre-proliferative (R2), proliferative (R3), maculopathy (M1)) in one or both eyes at any time after having bariatric surgery.

The study aims to establish the incidence of patients with new or worse sight-

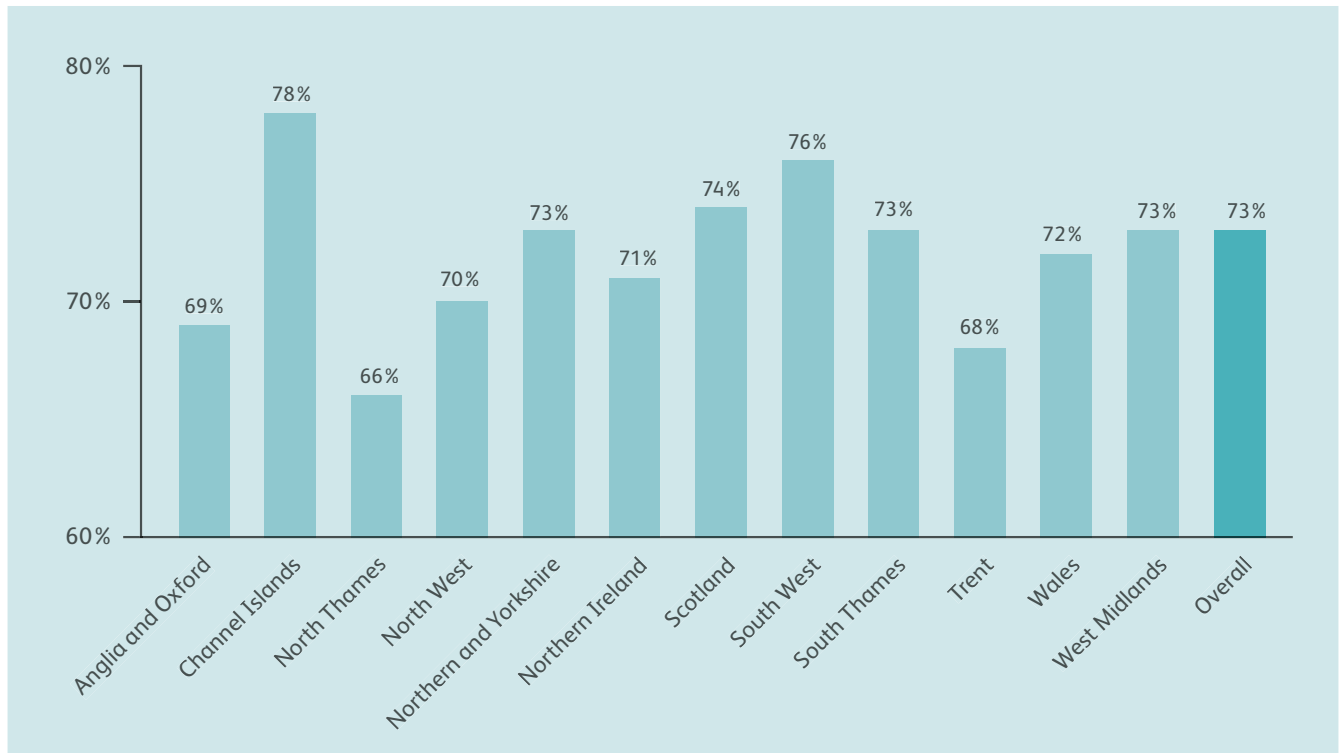
threatening diabetic retinopathy after bariatric surgery and describe the presenting features, current management and treatment needs along with the visual impact at 12 months.

We have received 1 report in the first month and we look forward to being able to provide feedback as the study progresses.

## Response Rates

The BOSU currently has 1462 ophthalmologists on the database. This is made up of 85 associate specialists; 1378 consultants and academic ophthalmologists.

The mean monthly card return rate for the past 6 months remains at 73%. The response rate from each of the regions is detailed in the graph below.



## Recent publications

### Recent Publications

1. Newsham D, O'Connor AR, Harrad RA Incidence, risk factors and management of intractable diplopia.. Br J Ophthalmol. 2017 Jun 28. [Epub ahead of print]
2. Moosajee M, Abbouda A, Foot B, Bunce C, Moore AT, Acheson J Active surveillance of choroidal neovascularisation in children: incidence, aetiology and management findings from a national study in the UK.. Br J Ophthalmol. 2017 Aug 26. [Epub ahead of print]
3. Chua PY, Day AC, Lai KL, Hall N, Tan LL, Khan K, Lim LT, Foot B, Foster PJ, Azuara-Blanco A. The incidence of acute angle closure in Scotland: a prospective surveillance study. Br J Ophthalmol. 2017 Aug 9. [Epub ahead of print]
4. Davies R, Watkins WJ, Kotecha S, Watts P The presentation, clinical features, complications, and treatment of congenital dacryocystocele Eye (Lond). 2017 Oct 27.. [Epub ahead of print]
5. Timlin HM, Hall HN, Foot B, Koay P Corneal perforation from peripheral ulcerative keratopathy in patients with rheumatoid arthritis: epidemiological findings of the British Ophthalmological Surveillance Unit. Br J Ophthalmol. 2017 Dec 15. [Epub ahead of print]

6. Maling S, King C, Davies N A British Ophthalmological Surveillance Unit Study on metastatic endogenous endophthalmitis. Eye (Lond). 2018 Jan 12. [Epub ahead of print]

### Presentations at College Congress Liverpool May 2017

#### Rapid Fire

1. UK National Surveillance of Emergency Canthotomy & Cantholysis - Dr Stephen Stewart, Royal Victoria Hospital, Belfast

#### Poster Presentations

2. Presumed Ocular Tuberculosis. A BOSU study. Interim findings, - Dr Kate Shirley, Belfast Health and Social Care Trust
3. 20 Years of rare eye disease surveillance: An Evaluation of The British Ophthalmological Surveillance Unit, - Mr Barnaby Foot, The Royal College of Ophthalmologists
4. The British Childhood Visual Impairment and Blindness Study (BCVIS2) - Ms Lucie Teoh, UCL GOS Institute of Child Health
5. Childhood uveitis not associated with juvenile idiopathic arthritis (JIA): Results from the national survey of incidence, management and visual outcomes. - Ms Su-yin Koay, Moorfields Eye Hospital

**For more information concerning the activities of this surveillance unit contact:**

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