Title page

Management of paediatric ocular inflammatory disease in the UK: national survey of practice.

AL Solebo,[1,2,3] JS Rahi,[1,2,3] C Edelsten,[1,2] JL Ashworth[4,5] and AD Dick,[3,6,7,8] on behalf of the Paediatric Ocular Inflammation Group

1. National Institute for Health Research Biomedical Research Centre at UCL Great Ormond Street Institute of Child Health and Great Ormond Street Hospital, London UK
2. Great Ormond Street Hospital for Children NHS Trust, London UK
3. National Institute for Health Research Biomedical Research Centre at Moorfields Eye Hospital NHS Foundation Trust and UCL Institute of Ophthalmology, London, UK
4. Division of Pharmacy and Optometry, School of Health Sciences, Faculty of Biology, Medicine and Health, The University of Manchester, Manchester, UK.
5. Manchester Academic Health Science Centre, Manchester Royal Eye Hospital, Manchester
6. Bristol Eye Hospital, University Hospitals Bristol NHS Foundation Trust, Bristol, UK
7. Pathology Department, Bristol Royal Infirmary, University Hospitals Bristol NHS Foundation Trust, Bristol, UK.
8. Translational Health Sciences, Faculty of Health Sciences, University of Bristol, Bristol, UK.

Corresponding Author (and address for reprints)

Ameenat Lola Solebo, Population, Policy and Practice Programme, UCL Great Ormond Street Institute of Child Health and Great Ormond Street Hospital, London UK

Lifecourse Epidemiology and Biostatistics Section, Population, Policy and Practice Programme, Institute of Child Health, University College London, London, UK

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Synopsis

From this national survey of the management of paediatric ocular inflammation, we report evidence of multi-disciplinary care, common use of systemic immunomodulation, and the need for support for transfer of care from exclusively paediatric services.

Eye and child health specialists have recently come together to form the Paediatric Ocular Inflammation Group (POIG).[1] POIG aims to inform management strategies, service commissioning and service delivery for children with sight threatening ocular inflammatory disorders. These disorders are united by their individual rarity, their complexity, and the use of potentially life-limiting systemic agents.

Using an online survey distributed through the Royal College of Ophthalmologists (Supplementary file), POIG sought to identify ophthalmic consultants routinely managing childhood uveitis or inflammatory ocular surface, orbital or optic nerve disorders. Of the 44 respondents, a third (17/44, 38%) managed all of these disorders (fig 1). Several specialists also managed adult disease: 14 of the 41 (46%) managing childhood uveitis; 10/27 (38%) orbital inflammation; 11/28 (39%) inflammatory ocular surface disorders (OSD); and 12 of the 22 (56%) ophthalmologists managing childhood optic neuritis. The majority had prescribed systemic immunomodulation / immunosuppression therapies: 30/41 in uveitis, 17/27 in orbital inflammation (idiopathic orbital n=10, vasculitis related n=4, sarcoidosis n=2, and Behcet disease n=1), 6/28 OSD (blepharitic keratoconjunctivitis, KC n=4, atopic KC n=2, herpetic keratitis n=1) and 14/22 in optic neuritis. Of those using systemic therapies, the majority did so as part of a multi-disciplinary team: 20/30 in uveitis, 15/17 in orbital inflammation, 14/14 in optic nerve disorders, and 5/6 OSD. Biological immunomodulation therapies had been prescribed (through rheumatology colleagues) by 28 specialists managing childhood uveitis.

Multi-disciplinary care was also reported in the surveillance of children at risk of uveitis due to Juvenile Idiopathic Arthritis. Examinations were carried out by allied health professionals in 12/38 (32%) settings (optometrists n=7, orthoptists n=5, nurses n=1).

In summary the majority of responding clinicians managed more than one disorder, and often as part of a multi-disciplinary team. Approximately half also manage adults. The survey was

'opt-in' in design, which may have resulted in under-ascertainment. However, an earlier national survey undertaken through the College identified a similar number (47) of UK surgeons managing congenital and infantile cataract,[2] a disorder which has an incidence of 3-4 per 10,000, thus ten-fold more common than childhood uveitis, which has a reported UK incidence of 5 per 100,000.[3] Nevertheless, there may have been under-ascertainment of clinicians managing mild disease.

Our findings suggest that half of all children with rare inflammatory eye disease are under specialists who do not manage adult disease. As the prognosis improves for children with rare eye disease, greater numbers will survive into adulthood with good vision. Effective transition processes are needed to prevent patient disengagement from care.[4] This is particularly important when care is shared between different services. We currently lack a consensus on best practice for transitional care for this group.

Collaborative national networks for rare disease have been recognised as a research priority by NHS England, particularly those networks which work to improve rare disease outcomes.[5] POIG has identified key clinicians managing these disorders (fig 1), and aims to develop the evidence base necessary to improve outcomes for individuals with (or at risk of) rare, childhood onset ocular inflammatory disorders.

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Titles and legends to figure.

Figure 1. Childhood ocular inflammatory disorders managed by survey respondents