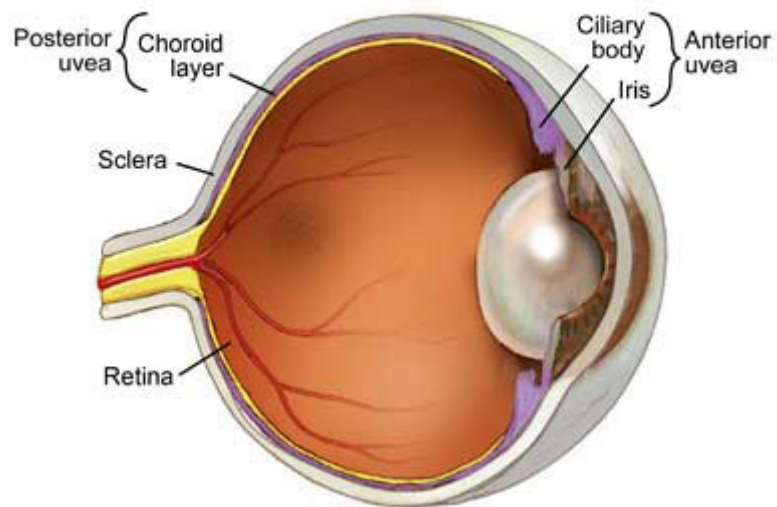


Uveitis

National Managed Clinical Network



Annual Report 2009-2010

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1 Introduction

This Annual Report has been prepared for the National Services Division by the Uveitis National Managed Clinical Network. The paper provides context and progress information on the network in the period April 2009 – April 2010.

The Network office is run from the Managed Clinical Networks Department within NHS Grampian. The Lead Clinician for the Network is Dr John Olson. The Network Manager is Lorraine Urquhart and the Network Support Manager is Frances Philip.

Description of Network

The Scottish Uveitis Network is an informal collaboration of clinicians and patient organisations, who believe that the most effective way of ensuring high quality, equitable care for patients with uveitis in Scotland is through a National Managed Clinical Network.

Purpose of the Network

The vision of the Scottish Uveitis Network is that by collaboration and multi-disciplinary working there will be a significant improvement in the outcome for people with sight-threatening uveitis.

Patients, particularly through the Uveitis Information Group, are at the centre of this patient-focused Network, which will act to ensure that equitable access to appropriate care is available to all.

Service Covered

Uveitis is an inflammatory eye disease and a significant, but largely unrecognised cause of visual impairment in the United Kingdom.

New and expensive developments for uveitis, such as anti-TNF therapy and other biologics, increase the importance of managing scarce resources, both financially and clinically, so that that the right patients receive the right treatment at the right time in the right place.

Membership

The Uveitis National Managed Clinical Network has an Executive Group, consisting of clinicians, a patient representative, who also represents the Uveitis Information Group, and a representative from the Royal National Institute of Blind People. There are three sub-groups, each chaired by a member of the Executive Group, with specific remits. These sub-groups feedback back to a much larger consultative Stakeholders Group, which will consider and discuss the proposals presented to them.

Resources/facilities

The Uveitis National Managed Clinical Network is not based within any one geographical area of discipline, but encompasses a diverse range of professionals and lay people from across Scotland. Co-ordination of the Network is done through the Managed Clinical Network Office in Grampian and members have been actively involved in the work of the Network through a series of face to face meetings, plus use of video and tele-conferencing and by e-mail discussions and updates on the work in progress.

2 Activity Report:

Members of the Uveitis National Managed Clinical Network have invested a great deal of time during 2009/2010 in consultation to draft and redraft various pieces of work which are core to the Network as a whole. This includes drawing up Clinical Standards; preparing Treatment Guidelines for the diagnosis and treatment of uveitis, mapping patient care across Scotland, and the preparation of a comprehensive set of patient information leaflets. A meeting was held with the Paediatric and Adolescent Rheumatology MCNs in October 2009 where it was agreed to develop a joint guideline to encompass both the adult and paediatric service.

Stakeholders' Group:

There were two Stakeholders Meetings in November 2009 and March 2010 to discuss the best way to take these processes forward and to agree the content of the documentation. Following these meetings, extensive use of electronic consultation was made to draft and redraft documentation to gain consensus on the content and form this should take. Good progress has been made in all aspects of this.

Clinical Standards Sub-Group:

The Clinical Standards Sub-Group have held meetings and have had discussions with NHS QIS in order to prepare quality assured standards of care for the diagnosis and treatment of uveitis, which will be applied across Scotland to ensure equity of care. Draft Clinical Standards have been presented to the Stakeholders' Meeting and following extensive discussions and consultation within the Sub-Group and at Stakeholders' Meetings, have been modified and re-drafted repeatedly. They will be presented again to a Stakeholders' Meeting in June 2010 for further consideration, discussion and approval.

Treatment Sub-Group:

The Treatment Sub-Group has developed a comprehensive Guideline for the diagnosis and treatment of uveitis to aid practitioners to recognise and treat this complex condition. They have mapped patient care across Scotland and there are clear links between the guideline and the patient information to ensure that the right kind of information to be given to the right person at the right time. This work has necessitated close co-operation between the Treatment Sub-Group and the Patient Information Sub-Group, to ensure that the links between the Guideline and the information leaflets being prepared for patients and others, is clear and that appropriate advice and information is available at every stage of the diagnostic and treatment process in the diverse presentations and types of uveitis.

Patient Information Sub-Group:

The Patient Information Sub-Group, which is a collaboration of patients, relatives and professionals, have produced a set of leaflets which aim to give patients, relatives and professionals, high quality, unambiguous, timely and relevant information about the condition, as and when required, with reference to where to find further information should they wish to do so. Consideration was taken to ensure that the level of readability was consistent and appropriate and that the RNIB guidelines on leaflet presentation were followed. This Group is working closely with the Clinical Standards and Treatment Guideline to ensure that the voice of the patient is heard throughout the development process. There are patient representatives on the Clinical Standards and the Treatment Guideline Sub-Groups. Extensive work has been done in order to prepare a range of information leaflets to cover different types of uveitis and to give patients at an appropriate time, the right level of information they require to deal with this condition, which might be a one-off occurrence or may be a long-term. Members of the Patient Information Sub-Group, in common with members of the other Sub-Groups, reside in many different places throughout Scotland and share a reliance on electronic forms of communication to ensure all members have access to documentation and are able to comment during the consultation process equally.

A Communication Plan for the Uveitis National Managed Clinical Network has been drawn up and is enclosed as Appendix A.

Audit Activity:

A baseline questionnaire was carried out from Clinicians throughout Scotland, prior to the launch of the Uveitis Network to ascertain which therapies were being used in each centre. A follow up study of the numbers of patients requiring systemic steroids, second line immunosuppression or a combination of these, and the use of biologics as a therapeutic option, was carried out at the beginning of 2009.

Data from the questionnaires was analysed and the results written up as a paper to be submitted to a medical journal, which is enclosed as Appendix B.

Research/Teaching:

With the agreement of the clinicians who provided the data, an analysis was performed and written up for publication in the Journal of Ophthalmology. It is envisaged that the Guideline and information leaflets will be an invaluable teaching resource for healthcare professionals in primary and secondary care, for Optometrists and for medical students, as this has been highlighted as an area currently lacking in coordinated teaching material.

Expenditure:

Description	Actuals at Year End	Projected Spend 2009/2010
Salaries and Wages	£46,319.19	
Travel & Admin Costs	£737.45	
Total	£47,056.64	

Plans/Objectives for the Year Ahead:

The Uveitis Stakeholders will meet in June 2010 in Aberdeen and by tele-link to other centres, to consider the latest drafts of the Clinical Standards, the Treatment Guideline and the Patient Information leaflets, which are the core elements to inform and establish the provision of equitable care for uveitis across all areas of Scotland.

Once agreement is reached as to the final version the Clinical Standards; to approve the Joint Guideline for the treatment of uveitis; and to give final approval to the information leaflets for patients they will be sent to various external bodies, such as the Royal College of Ophthalmologists, the Royal College of Physicians, the Royal College of General Practitioners and the Royal College of Physicians and Surgeons, Glasgow,, to the College of Optometrists and to the Royal National Institute of Blind People (RNIB) for approval.

Following approval, there will be a trial in one health board in Scotland to ensure the Guidelines are workable in clinical practice.

If approval is secured, the Joint Treatment Guideline, the Clinical Standards and the patient information leaflets will be distributed to every health board area in Scotland, in order to give clear direction and advice to ensure patients with uveitis are seen in the right place, at the right time by the right people to ensure equity of care across Scotland for people who suffer from this debilitating condition.

Appendix A

Communication Plan

**Uveitis National Managed Clinical Network
Communications Plan 2010/11**

	Deliverable	Audience	Description	Delivery Method	Frequency	Owner
Internal Meetings	Executive Team	Phil Hibbert John Legg Dr John Olson (chair) Dr Stuart Roxburgh Lorraine Urquhart Dr Graeme Williams	Update on key issues	Verbal discussion		all
	Clinical Standards Group	Phil Hibbert John Legg (Chair) Gill Ogden Dr John Olson Dr Stuart Roxburgh Vanessa Sandison Lorraine Urquhart Carri-Anne Walker	Update on progress of key projects.	Verbal discussion, with videoconferencing if required		John Olson
	Treatment Guideline Group	Dr Neil Basu Dr Chee Cheng Dr Nick Fluck Dr Janet Gardner-Medwin Dr Catherine Guly Dr Fraser Imrie Angela James Dr John Olson Dr Graeme Williams (Chair)	Update on progress of key projects.	Verbal discussion		John Olson
	Patient Focus Group	Carol Borland Stuart Borland Donald Cameron Phil Hibbert (Chair) Richard Lee Gill Ogden	Update on progress of key projects.	Verbal discussion		John Olson

		Dr Angus Scott Geraldine Shearer Caroline Smith Fiona Smith Emma Strathdee Caroline Taylor Lorraine Urquhart Carri-Anne Walker				
	Stakeholders	Claire Ballance Dr Neil Basu Carol Borland Stuart Borland Dr Suzanne Brannan Donald Cameron Dr Soma Chakrabarti Dr Chee Cheng Dr Bal Dhillon Mairi Duff Deirdre Evans Dr Brian Fleck Dr Nick Fluck Professor John Forrester Dr Janet Gardner-Medwin Dr Michael Gavin Dr Catherine Guly Dr Simon Hewick Phil Hibbert Dr Caroline Hind Dr Fraser Imrie Angela James Allan Jones Dr Lucia Kuffova Dr Manjula Kumarasamy Richard Lee Mr John Legg				

	Alison McAllister Dr David Mansfield Kirsty Martin Rea Mattocks Gillian Ogden Dr John Olson Dr Sheila Paterson-Brown Dr Alasdair Purdie Helen Robbins Dr Stuart Roxburgh Vanessa Sandison Angus Scott Geraldine Shearer Caroline Smith Fiona Smith Graeme Smith James Steven Emma Strathdee Caroline Taylor Lorraine Urquhart Dr Meena Virdi May Vobes Carri - Anne Walker Charlotte Ward Dr Graeme Williams Dr Mike Winter Dr Imran Zaheer				
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Health board survey

Methods

In order to establish the current level of service provision for uveitis in Scotland we sent a postal survey in 2008 to representatives from the 14 territorial health boards, all of whom were consultants or associate specialists involved in the care of patients with uveitis. Non-responders were contacted by e-mail. Mid-2008 population estimates were used to compare the size of the health boards (www.gro-scotland.gov.uk).

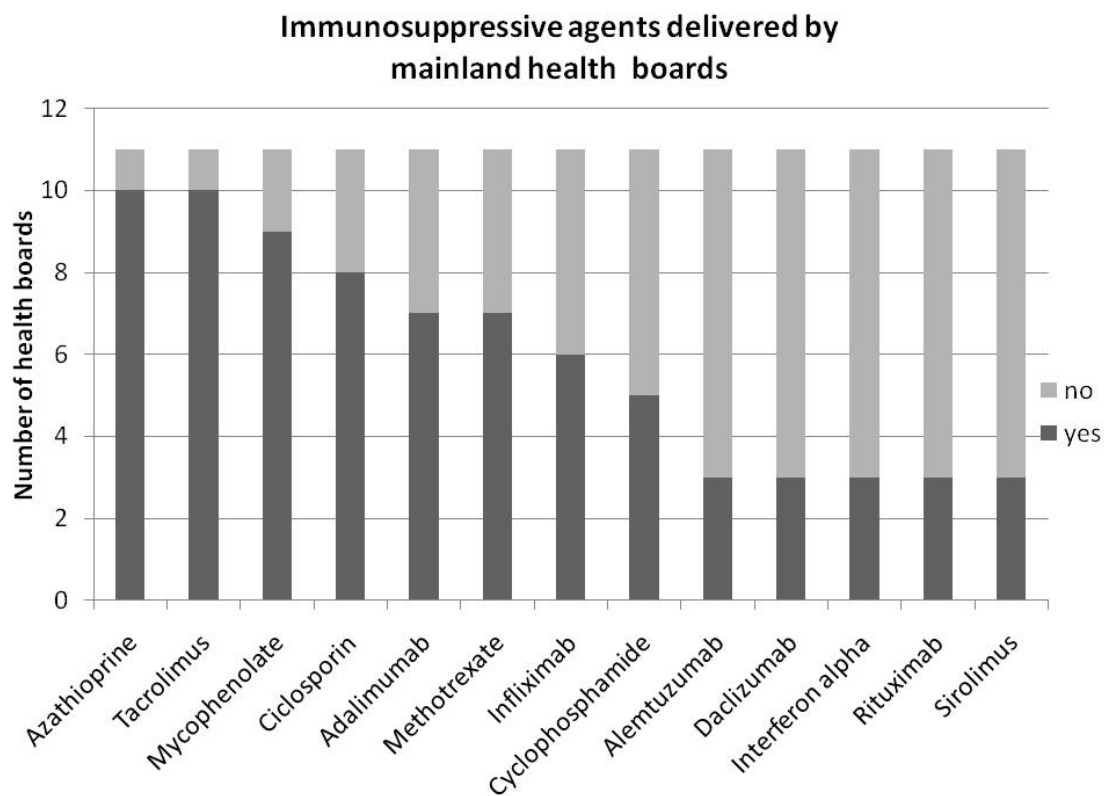
Results

All fourteen health boards responded to the questionnaire. There are permanent eye services in the 11 mainland health boards and the island health boards are served by visiting ophthalmologists or patients come to the mainland. Five mainland health boards run one or more uveitis clinics. Patients with chronic uveitis are followed up in general clinics in 6 health board and medical retina clinics in 6 health boards. In only two health boards are all patients with chronic uveitis followed up in a uveitis clinic.

There are three uveitis nurses working in two health boards for a total of three sessions. Their roles include running an anterior uveitis clinic, audit and research, patient counselling and blood monitoring for immunosuppression.

All mainland health boards offer second-line immunosuppressive therapy for uveitis although one health board only offers azathioprine. There are thirteen immunosuppressive agents used and azathioprine and tacrolimus are the most widely available, each being offered by 10 mainland health boards. Adalimumab is the most widely available biologic therapy and is delivered by seven health boards (Figure 1). No health board had denied funding of immunosuppressive therapy for uveitis in the previous year. In adult patients with no systemic involvement, immunosuppression is delivered by an ophthalmologist alone in ten health boards. Two health boards work with a non-ophthalmic physician to prescribe immunosuppression. The median health board population was larger for the health boards with a uveitis clinic than without (539,630 vs 299,974), and was larger for those offering biological treatments than those not (539,630 vs 255,198), but neither were statistically significant using the Mann-Whitney test (uveitis clinic $p=0.068$, biologics $p=0.059$) (Figure 2).

Figure 1.

**Figure 2.** Health board population and availability of services

Health board population (k)	Uveitis clinic	Uveitis nurse	Biologics
1,195	√	—	√
818	√	√	√*
561	—	—	√
540	√	—	√
397	—	—	√
368	√	—	—
362	√	√	—
310	—	—	√
290	—	—	√
149	—	—	—
112	—	—	—

*Paediatric service only

Uveitis survey

Method

NHS Scotland has fourteen territorial health boards which vary in geographical area and population and provide health care for patients within that locality. There was a restructuring of health boards in 2006 at which time Argyll and Clyde was dissolved. Highland now covers Argyll and Greater Glasgow and Clyde has formed as a new board.

Representatives from Ayrshire, Fife, Grampian, Greater Glasgow and Clyde, Lothian, Tayside and Shetland health boards prospectively collected data over a three month period from February to April 2009. Data was collected on patients who were resident in Scotland during the survey period. The time period of data collection was reduced from the previous survey in 2005 [10] to encourage participation and because it is usual practice to follow up patients on systemic therapy for uveitis at least once every three months, and often more frequently.

Data was collected on patients on systemic steroids or immunosuppressive agents for the treatment of uveitis during the survey period. Representatives were asked to specify which patients were on biological therapy. To prevent duplication of data (e.g. patients who attend more than one health board) and to allow patients to be linked to a health board, the following data was collected; the first part of the postcode, gender, age and the last four digits of the community health index number. The first part of the postcode was used to allocate patients into their local health board. For the small number of patients (3%) who live in a postcode which is covered by more than one health board, their local health board was taken to be the one which collected their details. Data was collected on adults and children but the paediatric data was incomplete and so only the data on adults (aged 18 years or over) was analysed. The community health index number is a unique patient identifier used throughout NHS Scotland. Use of the last four digits only maintains anonymity. Patient data was made anonymous in accordance with the Confidentiality and Security Advisory group for Scotland guidelines [11] and was forwarded each month to the Uveitis NMCN support manager in Aberdeen.

Results

The adult population of Scotland in 2008 was estimated at over 4.1 million.[12] A total of 396 adult patients on systemic therapy for uveitis were identified in the survey. There were 238 female patients (60.1%). The age range was 18 years to 94 years with a mean of 48.8 years and median of 48 years. Postcodes were provided for 393 patients (99%) and this was used to determine the numbers of patients per health board and the prevalence of systemic therapy use per 100,000 persons.

Using data from the seven participating health boards, there was an estimated prevalence of patients on systemic therapy for uveitis of 11.8 per 100,000 in Scotland. Ayrshire had the lowest prevalence per 100,000 at 7.2 and Shetland had the highest at 52.7. (Figure 1)

There were 36 patients (9.1%) recorded as currently receiving biological therapy. Of the mainland health boards, Grampian had the highest prevalence of biologic use with 2.8 patients per 100,000 being treated (14.5% of patients on systemic treatment) and Ayrshire had the lowest at 0. Overall, Shetland had the highest prevalence of biologic use (11.7) but with only two patients being treated, numbers are too small to make a meaningful comparison. Data on the type of biological agent used was available for 92% of patients. Interferon alpha was the most commonly used biological agent (Figure 2).

Figure 1.

