# Set up of a retinal screening registry for patients with haemoglobinopathies ensuring regular screening to detect sight-threatening sickle retinopathy

*Maja Bilip[1] Charlotte Lees[2], Noemi Roy[2] Susan M Downes [1,3]*

1 Oxford Eye Hospital, John Radcliffe Hospital, Oxford, UK

2 Department of Haematology, Oxford University Hospitals, NHS Foundation Trust, Oxford, 3 Nuffield Laboratory of Ophthalmology, University of Oxford

## AIM

To set up a registry for retinal screening of patients with haemoglobinopathies to enable timely detection of sight threatening retinopathy requiring intervention.

## METHODS

Following a literature review, the existing local guidelines for sickle retinopathy (SR) screening were updated. This formed the standard against which data in this project was compared.

All patients with a haemoglobinopathy:

- From age 12 should have 2-yearly screening with visual acuity, ultra-wide field imaging of the fundus or clinical dilated fundus examination.
- > 18 years of age should have annual retinopathy screening – this should include visual acuity, ultra-wide field imaging of the fundus or clinical dilated fundus examination.
- Over age 50 with no signs of sickle cell retinopathy should be discharged to standard optometry care.
- If proliferative disease is identified, referral to a Retinal Specialist with specific expertise is required.
- The frequency of review, or intervention will be determined at this point.

Patients requiring retinal screening were identified from the Haematology database at the OUH Trust. Microsoft Excel was used for data storage and analysis.

The following baseline data was collected from the electronic patient record for each patient: demographics, type of haemoglobinopathy, previously identified sickle retinopathy, previous interventions required, last follow up date, current follow up frequency, number of appointments not attended. The registry is stored using Excel in a secure password protected folder only accessible from trust computers.

Data included in the registry was limited to demographic data, last follow up date and current follow up frequency. Recommended follow up frequency and next suggested date for follow up / next booked appointment were then added to the data set as part of the registry to allow for monitoring of screening frequency.

A recommended date for screening was applied for each patient. Once the registry was activated overdue patients were contacted and offered an appointment. The registry was checked against the project standard for each patient for the first audit cycle after one month and 12 months using electronic patient records. The registry was kept up to date by the responsible consultant and personal assistants in the ophthalmology department.

## RESULTS

47 patients were identified. 6 patients were new to the area and were awaiting referral to the department. 3 patients were discharged or had deceased during the course of the project. These patients were excluded from data analysis at 1 and 12 months.

At baseline, 18 (45%) of patients were screened according to the recommended standard. 18 (45%) patients were overdue for screening. 4 (10%) had appointments, but the timing was not in line with the guidelines.

**Figure 1:** Percentage of patients undergoing screening in line with guidance at baseline, 1 and 12 months following registry implementation

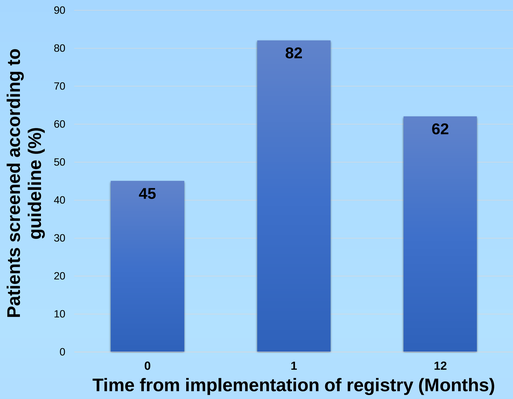



**Image 1:** Wide field retinal imaging of sea-fan neovascularisation in a patient with proliferative sickle cell retinopathy. Image curtesy of Professor S.M. Downes.



## RESULTS (cont.)

At one month 13 (65%) patients with overdue appointments were booked in for screening as a direct result of the creation of the registry. 1 (17%) patient not known to the local ophthalmology service was referred for screening. This reduced the number of patients who were overdue for screening from 18 (45%) to 7 (18%).

One year after registry implementation, 25 (62%) patients were in appropriate follow up and 14 (38%) were overdue screening. Of these, 50% had no appointment yet made, and 50% failed to attend the appointments sent to them (Figure 2).

## CONCLUSION

- Introduction of the registry has led to an increase in the proportion of patients undergoing timely retinal screening.
- The registry is a time-efficient and effective way of recording patient screening.
- Further intervention is required to achieve >80% compliance.
- Persons responsible for keeping the registry up to date, liaising with the Ophthalmology department, and adding new patients onto the registry must be further specified. We propose that these responsibilities lie with the haemoglobinopathy coordinator who will coordinate with the ophthalmology personal assistants to ensure full coverage and timely screening. The haematology and ophthalmology consultants will be involved in annual audit of the registry.
- The next audit cycle should focus on addressing the high proportion of appointments not attended.

**Figure 2:** Reason for overdue appointments 12 months after implementation of registry

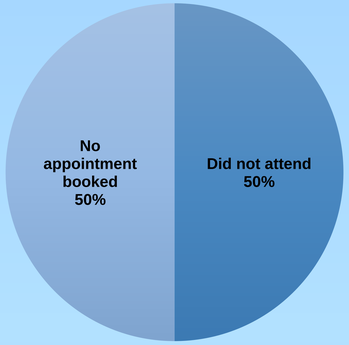
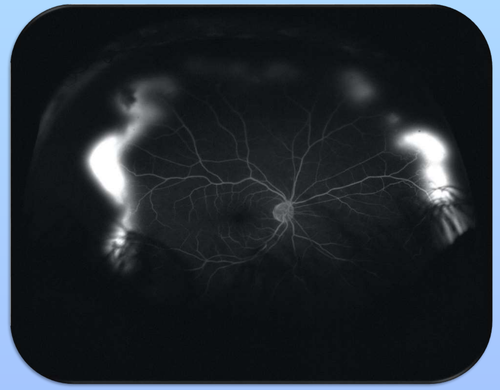



**Image 2:** Fluorescein angiography of a patient with sickle cell retinopathy demonstrating 360º sea-fan neovascularisation. Image curtesy of Professor S.M. Downes.



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