



HEALTHCARE SAFETY
INVESTIGATION BRANCH

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SUMMARY REPORT LACK OF TIMELY MONITORING OF PATIENTS WITH GLAUCOMA

Healthcare Safety Investigation I2019/001

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A NOTE OF ACKNOWLEDGEMENT

We are grateful to the patient whose experience is central to this investigation. In accordance with her wishes, she is referred to as *'the patient'* throughout this report. The information she shared helped to inform the investigation and provided invaluable insight into the impact of such incidents. The patient hoped that her story might promote change.

We also thank the NHS staff and subject matter advisors who gave their time to provide information and expertise which contributed towards this report, and the stakeholder organisations and professional bodies that have supported the investigation.

ABOUT HSIB

The Healthcare Safety Investigation Branch (HSIB) conducts independent investigations of patient safety concerns in NHS-funded care across England.

Most harm in healthcare results from problems within the systems and processes that determine how care is delivered. Our investigations identify the contributory factors that have led to harm or have the potential to cause harm to patients.

The recommendations we make aim to improve healthcare systems and processes in order to reduce risk and improve safety.

Our organisation values independence, transparency, objectivity, expertise and learning for improvement.

We work closely with patients, families and healthcare staff affected by patient safety incidents, and we never attribute blame or liability to individuals.

OUR INVESTIGATIONS

Our investigators and analysts has diverse experience working in healthcare and other safety-critical industries and are trained in human factors analysis, safety science and the design of safety management systems. We consult widely in England and internationally to ensure that our work is informed by appropriate clinical and other relevant expertise.

We undertake patient safety investigations through two programmes:

NATIONAL INVESTIGATIONS

Our national investigations can encompass any patient safety concern that occurred within NHS-funded care in England after 1 April 2017. The topics we select are informed by suggestions provided by healthcare professionals and the public, and our own analysis of NHS patient safety databases and reporting.

We decide what to investigate based on the scale of risk and harm, the impact on individuals involved and on public confidence in the healthcare system, as well as the potential for learning to prevent future harm. We welcome information about patient safety concerns from the public, but we do not replace local investigations and cannot investigate on behalf of families, staff, organisations or regulators.

Our investigation reports identify opportunities for relevant organisations with power to make appropriate improvements through:

- *'Safety recommendations'* made with the specific intention of preventing future, similar events
- *'Safety observations'* with suggested actions for wider learning and improvement.

Our reports also identify *'safety actions'* taken during an investigation to immediately improve patient safety.

We ask organisations subject to our safety recommendations to respond to us within 90 days. These responses are published on the investigation pages of our **website**.

MATERNITY INVESTIGATIONS

Since 1 April 2018, we have been responsible for all patient safety investigations of maternity incidents occurring in the NHS in England which meet criteria for the **Each Baby Counts programme**.

The purpose of the HSIB maternity investigations programme is to achieve rapid learning and improvement in maternity services, and to identify common themes that offer opportunity for system-wide change. For these incidents HSIB's investigation replaces the local investigation, although the NHS trust remains responsible for meeting the Duty of Candour and for referring the incident to us.

We work closely with parents and families, healthcare staff and organisations during an investigation. Our reports are provided directly to the families involved and to the trust. The trust is responsible for actioning any safety recommendations we make as a result of these investigations.

Our longer-term aim is to make safety recommendations to national organisations for system-level improvements in maternity services. These recommendations will be based on common themes arising from our trust-level investigations.

EXECUTIVE SUMMARY

Introduction

In this investigation we explore the issues influencing the lack of timely monitoring of patients with glaucoma¹. As an example, which we refer to as the *'reference event'*, we consider the experience of a 34-year-old woman who lost sight as a result of delayed follow-up appointments. The investigation makes recommendations for the management and prioritisation of such appointments. The findings and conclusions of this investigation are likely to be applicable to follow-up of patients with other eye conditions, or conditions that fall within other specialties.

The reference event

The patient visited a high-street optician because she was concerned about her vision. She was subsequently diagnosed with glaucoma by a community ophthalmologist² who started her on treatment to lower her intraocular pressures and referred her to the local hospital eye service (HES) for an urgent assessment. Due to a lack of available appointments, there was a delay in the patient being seen. When she was seen, it was noted that she had advanced visual field loss. The patient was reviewed on several occasions over the next couple of months, with investigations performed and different eye drops prescribed.

Due to a lack of capacity within the HES, there followed a series of delays in the patient's follow-up appointments over the course of 13 months. The patient recalled phoning the HES on a number of occasions about her sight and the delays. She was seen by seven different ophthalmologists during this time, of whom three were locum consultants and two were trainees. Despite changes in treatment, her intraocular pressures were not stable and eventually laser surgery was performed. The cumulative delays that occurred between the time of her referral to the HES and her laser surgery totalled 11 months. By this time her sight had deteriorated to the point where she was registered as severely sight impaired.

A consultant completed a clinical incident report³ regarding the appointment delays. Following a review of the patient's care, it was agreed that there had been missed opportunities to preserve her already limited sight, and that this had left her significantly disabled and unable to lead a normal life.

The national investigation

The lack of timely monitoring for patients with glaucoma is a nationally recognised patient safety risk. The Healthcare Safety Investigation Branch (HSIB) contacted the hospital where the reference event occurred after it was referred for potential investigation. Following initial information gathering and evaluation against the HSIB patient safety risk criteria (see 3.2), HSIB's Chief Investigator authorised a national safety investigation.

The objective of the investigation was to understand the context and contributory factors influencing the lack of timely monitoring of patients with glaucoma. The investigation assessed the risk controls in place to mitigate the safety risk and identified opportunities for improvement. It visited organisations that had implemented risk-reduction systems and processes to share learning from their experience.

Findings

The investigation found:

- There is inadequate HES capacity to meet the demand for glaucoma services. Current capacity can be maximised by ensuring referrals to, and follow-ups by, HESs are appropriate and by introducing new ways of working.
- The vast majority of suspected glaucoma referrals to HESs are from primary care optometrists⁴. A significant proportion of the patients referred are subsequently found not to have glaucoma. To reduce the number of such referrals many localities have commissioned glaucoma filtering schemes.
- Risk averse behaviours by some doctors have resulted in unnecessary, or unnecessarily frequent, follow-up appointments and tests, which have exacerbated capacity issues. This seems to be a particular concern in clinics run by locums, trainees or ophthalmologists who are not specialists in glaucoma. These doctors are used to cover shortfalls in consultant ophthalmologist numbers or in an attempt to create extra capacity to reduce appointment backlogs.

¹ Glaucoma can be regarded as a group of eye conditions that results in damage to the eye's main nerve (the optic nerve). The condition gets worse over time and can cause loss of sight. Glaucoma is usually associated with an increase in the pressure of fluid inside the eye, known as intraocular pressure.

² Ophthalmologists are medically trained doctors who specialise in the treatment of eye diseases and injuries.

³ Staff are expected to report incidents which could have, or have, resulted in harm to patients. This forms part of an organisation's risk management. All incidents are submitted to a national database. NHS England/Improvement use the data to publish official statistics and to identify patterns and trends.

⁴ Optometrists are eye health professionals who have undergone specialist training to examine, diagnose and treat eye conditions, but are not medically trained doctors.

- Redesigned pathways that enable other adequately trained members of the multidisciplinary team to take on tasks previously performed by ophthalmologists have been shown to safely increase capacity.
- Virtual clinics can be an efficient use of resource for assessing new referrals and follow-up of patients who are at low or medium risk of disease progression.
- There are significant differences in the risk of vision loss within the cohort of patients with glaucoma. The categorisation of patients according to their risk of sight loss (a process known as risk stratification) would allow follow-up appointments to be prioritised according to clinical need.
- There is sufficient evidence regarding alternative ways of working to develop models for the optimal delivery of glaucoma care.
- The national mandated (that is, formally required by the NHS Constitution) 18-week referral to treatment target has resulted in newly referred patients being prioritised over follow-up patients. Within ophthalmology, follow-up patients with glaucoma are at the greatest risk of avoidable sight loss.
- Strengthening assurance and accountability arrangements for HESs' reporting of compliance against the follow-up performance standard in the Portfolio of Indicators for Eye Health and Care (a set of standards for care developed by Vision UK's Ophthalmic Public Health Committee) is likely to be beneficial in driving improvement.
- HESs have been asked to collect and submit follow-up data to allow delays to be reported nationally. Few HESs are submitting this data. Mandating its collection would improve this.
- To enable data regarding risk stratification of patients to be reported centrally, a new field would need to be created on the patient administration systems used in HESs. Completion of this field should be mandated.
- The financial tariff (the amount a health service provider is paid) for a follow-up appointment is less than for a new appointment, which has created a further incentive to prioritise initial appointments.
- Consultants are increasingly seeing more complex cases in follow-up clinics, meaning fewer patients can be seen per clinic. The financial tariff needs to reflect this.
- The current tariff does not encourage new ways of working, which are needed if the NHS Long Term Plan to reduce face-to-face, hospital-based appointments is to be realised.
- High Impact Interventions issued by NHS England detailed the risk controls needed to reduce the risk of harm to patients caused by lack of capacity. While national leadership has driven forward change, these risk controls are not fully in place in many trusts.
- Work in Bristol has shown proof of concept for a more refined, more predictive risk stratification model based on progression of visual field loss over time and clinical markers. Further research is needed to assess reproducibility and workability.

HSIB MAKES THE FOLLOWING SAFETY RECOMMENDATIONS

Safety recommendation R/2020/059:

It is recommended that the Royal College of Ophthalmologists, working with relevant stakeholders, develop models and review workforce required for the optimal delivery of glaucoma care.

The models should be tested and evaluated.

Safety recommendation R/2020/060:

It is recommended that NHS England/Improvement require commissioners to agree, under their service contracts, the action that providers will take to ensure compliance with the Portfolio of Indicators for Eye Health and Care follow-up performance standard. Where the standard has not been met, there should be a requirement for providers to demonstrate that they have reviewed individual pathways and taken action to mitigate risk, as well as to understand the causes of any unnecessary delays to inform improvement.

Safety recommendation R/2020/061:

It is recommended that NHS England/Improvement commission NHS Digital to publish reports of hospital eye services' compliance with the follow-up appointments performance standard included in the Portfolio of Indicators for Eye Health and Care.

Safety recommendation R/2020/062:

It is recommended that NHS England/Improvement review the payment for the ongoing management of patients with glaucoma, regardless of setting. Pricing should reflect the complexity and costs of follow-up appointments and encourage new ways of working.

Safety recommendation R/2020/063:

It is recommended that NHS Digital include provision for identifying, prioritising and monitoring patients at risk of developing sight loss within the next version of the national Commissioning Data Set. Provision should include the ability to record a risk rating and the recommended follow-up date for each patient, meaning these are mandated data items for collection by hospital eye services.

This should be carried out in consultation with key stakeholders such as the Royal College of Ophthalmologists and patient administration system suppliers.

Safety recommendation R/2020/064:

It is recommended that the Royal College of Ophthalmologists agree criteria for the risk stratification of patients with glaucoma so that practice can be standardised across NHS hospital eye services.

Safety recommendation R/2020/065:

It is recommended that the International Glaucoma Association facilitate the funding of research into the development and evaluation of an automated, predictive risk stratification tool.





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FURTHER INFORMATION

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 @hsib_org is our Twitter handle. We use this feed to raise awareness of our work and to direct followers to our publications, news and events.

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