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HEALTHCARE SAFETY INVESTIGATION BRANCH

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INTERIM BULLETIN

LACK OF TIMELY MONITORING OF PATIENTS WITH GLAUCOMA

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This interim bulletin contains facts which have been determined up to the time of issue. It is published to inform the NHS and the public of the general circumstances of events and incidents and should be regarded as tentative and subject to alteration and correction if additional evidence becomes available.

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NOTIFICATION OF EVENT AND DECISION TO INVESTIGATE

The lack of timely monitoring of patients with glaucoma was identified by HSIB as a patient safety risk priority for investigation. The reference event was referred to HSIB by the legal representative dealing with a patient's claim for negligence. The Trust where the reference event occurred had reported it as a serious incident on the national serious incident database (Strategic Executive Information System - StEIS). HSIB contacted the Trust and a preliminary, scoping investigation was commenced. The purpose of scoping investigations is to explore the identified patient safety risk(s), and to consider the practicality and value of proceeding to a national investigation. The Trust welcomed HSIB involvement and collaborated with information gathering.

Following the preliminary investigation, the Chief Investigator authorised a full investigation as the risk met the following criteria:

Outcome Impact – what was, or is, the impact of the safety issue on people and services across the healthcare system?
Lack of timely monitoring of patients with glaucoma can cause premature sight loss and blindness.

The quality and reliability of ophthalmology services are affected by the inability to effectively monitor and control backlogs of patients needing appointments.

As well as the human cost, such incidents undermine patient confidence and trust in healthcare services. They also incur a financial burden and damage a hospital's reputation.

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Systemic Risk - How widespread and how common a safety issue is this across the healthcare system?

The safety risk has a wide geographic spread reflecting the systemic nature of the issue. A search of the national serious incident reporting database identified 103 reported incidents between 1 April 2017 and 31 December 2018 (20 months) which directly referenced issues with ophthalmology monitoring and follow-up processes (this included patients with other chronic eye conditions such as age-related macular degeneration). Seven reports were related to groups of patients and/or incidents, the exact number of patients affected was not given. A further search on StEIS between the same dates analysed reported incidents specifically involving glaucoma outpatient follow-up for contributory factors and key findings. Of the 80 incidents, 24 had not identified contributory factors or given key findings. Of the remaining 56, 27 (48%) acknowledged capacity issues and 29 (52%) acknowledged issues in processes (such as inadequate risk stratification and prioritisation of patients).

In April 2009 (updated in 2017) the National Institute for Health and Clinical Excellence (NICE) released guidelines for the assessment and treatment of glaucoma including standards for follow-up. To complement the 2009 guidelines, the National Patient Safety Agency (NPSA) published a Rapid Response Report[1]. This report detailed incidents resulting in harm and made recommendations to prevent delay to follow-up. The recommendations were directed at ophthalmology services and organisations that commissioned ophthalmology services. Despite these guidelines and recommendations, the timely monitoring of patients with glaucoma has persisted as a patient safety risk.

[1] National Patient Safety Agency (NPSA), *"Rapid Response Report. Preventing Delay To Follow Up For Patients With Glaucoma,"* 2009

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The British Ophthalmological Surveillance Unit found that up to 22 people per month were experiencing permanent and severe visual loss due to health service-initiated delays.

There are contextual challenges regarding the timely monitoring of patients with glaucoma. In particular, there is a mismatch between demand and capacity. Ophthalmology is the highest volume outpatient specialty in England[2] and the volume is increasing each year. The 2018 report by the All-Party Parliamentary Group on Eye Health and Visual Impairment states: *'The number of people in the UK that will be affected by sight loss is projected to increase by over 10 per cent by 2020 and by over 40 per cent by 2030[3].'* Modelling of future demand has predicted that from 2015 to 2035, the number of people in the UK with glaucoma will rise by 44% (22% rise from 2015 to 2025)[4].

Learning Potential – What is the potential for an HSIB investigation to lead to positive changes and improvements to patient safety across the healthcare system?

Despite recognition of the risk and recommendations made to address it ten years ago, the risk has remained. Initial information gathered by the investigation identified that some Trusts have made changes which have had a beneficial impact on managing the risk. There may be opportunities to share learning to positively influence processes and practices across organisations.

[2] This is based on hospital episode data for 2017/18 (the latest available): **https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics**

[3] All-Party Parliamentary Group on Eye Health and Visual Impairment, *"See the light: Improving capacity in NHS eye care in England,"* 2018.

[4] The Royal College of Ophthalmologists, *"The Way Forward: Glaucoma,"* 2017.

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HISTORY OF THE EVENT

The patient, a 34-year-old woman, visited a high street optician with concerns about her vision. She was subsequently diagnosed with glaucoma and started on treatment to lower her intraocular pressure. The patient was referred for urgent assessment in the Eye Unit at her local hospital. There was a delay in the patient's first appointment but when she was seen it was noted that she had advanced visual field loss. The patient was seen on several occasions over the next couple of months, with investigations performed and different eye drops prescribed.

Due to a lack of capacity, there followed a series of delays in the patient's follow-up appointments over the course of 13 months. The patient recalled phoning the Eye Unit on a number of occasions about her sight and the delay in appointments. She was seen by several different ophthalmologists at her appointments. Despite changes in treatment, her intraocular pressure was not stable and eventually laser surgery was performed. From the time of her referral to the Eye Unit to her laser surgery, the time delays in appointments added up to a total of 11 months. By the time of her laser surgery, her sight had deteriorated to the point where she was registered as severely sight impaired.

An incident form was completed by a consultant ophthalmologist regarding the appointment delays. Following review of her care by the Trust, it was concluded that there had been a missed opportunity to preserve the patient's already limited sight, which had left her significantly disabled and unable to lead a normal life.

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NATIONAL CONTEXT

The lack of timely monitoring for patients with glaucoma is a nationally recognised patient safety risk, and delays to treatment have been found to cause harm[1,3]. In 2018 NHS England issued High Impact Interventions for Trusts responsible for Hospital Eye Services and commissioners to help minimise the risk of harm for patients with chronic eye conditions[5]. Other recent national reports have proposed to reduce treatment delays through increasing capacity and managing demand[4,6]. However, demand for eye services is predicted to rise further with an ageing population and the availability of new treatments to prevent sight loss. This creates an imperative to address capacity challenges in a sustainable way.

IDENTIFIED SAFETY ISSUES

The HSIB has analysed the reference incident, applying a human factors-based approach, to examine the systemic issues which contributed to the sequence of events. The following safety issues were identified and will form the basis of the ongoing investigation:

- The lack of capacity for follow-up appointments has been an increasing problem over years. Whilst there has been an awareness of the issue, the scale of the problem, and the risk of harm patients were exposed to, has not been fully appreciated by all relevant stakeholders. There has been a lack of forward planning to cope with the increasing demand.

[5] NHS England, *"Elective Care High Impact Interventions: Ophthalmology Specification,"* 2018.
[6] Royal College of Ophthalmologists, *"Commissioning Guide: Glaucoma,"* 2016.

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- Processes and patient administration systems have often not facilitated effective oversight of the issue or supported staff in prioritising scarce appointments to those at greatest risk of loss of vision.

- Lack of space in Hospital Eye Services can limit the adoption of different ways of working, hampering opportunities to increase capacity.

- The national 18 week referral to treatment target, and the requirement to report compliance, has focused attention on first appointments for new patients. There has not been an equivalent focus on follow-up appointments being booked within the requested (clinically indicated) timescale.

- The financial tariff for follow-up appointments is less than first appointments. This creates an incentive to prioritise first appointments into a service rather than follow-ups. However, for patients with glaucoma, those requiring follow-up are more likely to have a sight threatening condition that needs long-term monitoring and treatment[7].

NEXT STEPS

The HSIB investigation will continue to explore the identified safety issues and welcomes further information that may be relevant, regardless of source.

[7] Royal College of Ophthalmologists , *"Three Step Plan: Reducing risk for eye patients - improving timely care,"* 2016.