Lack of Timely Monitoring of Patients with Glaucoma

Healthcare Safety Investigation I2019/001

January 2020 Edition
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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

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 investigators and analysts have 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 glaucoma (note 1). 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 ophthalmologist (note 2) 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 report (note 3) 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 optometrists (note 4). 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.

- 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 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.

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.
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1 Background

1.1 Management of glaucoma

1.1.1 Glaucoma can be regarded as a group of eye conditions that result in damage to the main nerve in the eye (the optic nerve) and loss of visual field [1, 2, 3]. It is usually (but not always) associated with an increase in the pressure of the fluid inside the eye (intraocular pressure) to above the normal range, and can result in loss of vision [1]. Eye pressure is measured in millimetres of mercury (mmHg) and the normal range is between 10 and 21mmHg (note 5). Glaucoma is the leading cause of irreversible blindness in the world [4] and the second most common cause for registration of visual impairment in England and Wales [1].

1.1.2 Glaucoma is classified into two major categories according to the appearance and obstruction of the drainage canal in the eye, known as the trabecular meshwork (see Figure 1). The two categories are open angle glaucoma and closed angle glaucoma. In open angle glaucoma, although the drainage pathway looks normal, there is resistance to the drainage of a fluid called the aqueous humour. In closed angle glaucoma, tissue physically

5 National Institute for Health and Care Excellence guidance states whilst 21mmHg is widely accepted as the upper limit of normal range, there is uncertainty about treatment for people with an intraocular pressure above 21mmHg but below 24mmHg. Referral to hospital eye services for further investigation and diagnosis is therefore recommended for an intraocular pressure of 24mmHg or above [8].
Fig 1  The difference between a healthy eye and an eye with glaucoma

Normal Eye

Drainage canal blocked. Too much fluid stays in the eye this increases pressure

Glaucoma

High pressure damages optic nerve
obstructs the drainage pathway preventing the outflow of fluid. Glaucoma is also classified according to whether it is primary (which accounts for over 70% of cases) or secondary (associated with other diagnosed illnesses) [1].

1.1.3 The natural course of primary open angle glaucoma is variable and time dependent. Characteristic abnormalities associated with the condition can be detected through a number of different eye tests, particularly a change in the appearance of the optic nerve known as ‘optic disc cupping’. In most patients these abnormalities progress slowly, over years, and patients remain without symptoms despite loss of peripheral (side) vision, retaining good central vision (visual acuity) until late in the disease.

Patients with early glaucoma are, therefore, typically unaware that they have it. By the time patients start to show symptoms of open angle glaucoma, severe and irreversible damage has usually occurred to the visual field in one or both eyes [1].

1.1.4 Risk factors for primary open angle glaucoma include a family history of the disease, being of African, Caribbean or Asian ethnicity, age (the disease is most common in adults over 70-years-old), high intraocular pressure and being treated with systemic or topical corticosteroids (steroid creams) [2, 4].

1.1.5 As glaucoma is more common in older people, the number of those with the condition is expected to rise significantly in the UK due to the ageing population. Forecasts have predicted a 44% increase
in the number of people with glaucoma between the years 2015 and 2035 [5, 6]. The resulting increase in demand for services will place capacity pressures on hospital eye services (HESs). The availability of new technology and treatments also impacts on demand.

1.1.6 Sight loss caused by glaucoma cannot be recovered, but further damage can be prevented or slowed with early diagnosis, careful monitoring and regular use of treatment, which is usually directed at lowering intraocular pressure [3].

1.1.7 As glaucoma cannot be cured, patients require lifelong monitoring and treatment [7]. It is a condition commonly encountered by NHS HESs, with more than one million glaucoma visits per year [1].

1.1.8 Following a glaucoma diagnosis, the management of the condition aims to prevent visual disability/loss during a patient’s lifetime or to prevent further deterioration of visual disability [1]. The patient’s condition is managed through ongoing monitoring of their intraocular pressure (IOP), optic nerve appearance and visual field. A target pressure is set at a level which is believed to be enough to prevent progression of the condition [1]. Treatment is used to lower the patient’s intraocular pressure to the target level and includes medical, laser and other surgical options [1].

1.1.9 In 2009 the National Institute for Health and Care Excellence (NICE) published guidance on the diagnosis and management of glaucoma. The guidelines were updated in 2017. The guidelines,
which are supported by quality standards, include the recommended time interval to next assessment (follow-up) for people diagnosed with chronic open angle glaucoma based on the risk of progression to sight loss [8].

1.1.10 To complement the release of the NICE guidance in 2009, the National Patient Safety Agency (NPSA) issued a Rapid Response Report highlighting harm caused to patients with glaucoma as a result of delayed or cancelled follow-up appointments [9]. The report included a number of recommendations for immediate action. These included: ensuring booking systems flagged the clinical priority of the appointment; identifying and monitoring the number of patients awaiting follow-up; and confirming there was sufficient capacity within the local health community to meet the need for outpatient appointments and specialist eye investigations such as visual field testing.

1.1.11 Despite the NPSA report, the risk of harm to patients with glaucoma as a result of delayed follow-up has persisted [10, 11]. So too has the need for systems that enable prioritisation of appointments by highlighting numbers of patients awaiting follow-up and those at greatest risk of losing their sight [12, 13]. This indicates that future recommendations should have some binding elements such as those provided by contractual or mandatory requirements.
2 The Reference event

2.1 The patient’s story

2.1.1 The patient, a 34-year-old woman, came to England in May 2015 to join her husband. In November that year, she began to notice that her right eye “felt blurry and unclear...as if something was in my eye”. This didn’t improve, and on 16 June 2016 the patient visited a high-street optician who advised her that her GP would need to make a referral to the community ophthalmology service (note 6). The optician sent a letter the same day to the patient’s GP stating that she needed an urgent ophthalmology referral. The letter was stamped as received in the GP practice on 20 June. The patient had an appointment booked with the GP on 30 June but was unable to attend. On 1 July 2016 her GP made the referral and the patient was informed. She contacted the ophthalmology service (note 7) on 6 July and booked an appointment for 20 July.

2.1.2 The patient was assessed by an ophthalmologist at the community ophthalmology service on that day and was described as having ‘advanced optic disc cupping and dense field defects, worse in her right eye’ (features of advanced glaucoma). The ophthalmologist prescribed eye drops (note 8) and referred her to a consultant ophthalmologist (consultant A) at the local hospital eye service (HES) for an urgent assessment. The diagnosis of primary open angle glaucoma in both eyes was included on the referral form along with intraocular pressures (IOP) of 26mmHg in both eyes.
The referral was received by the Patient Services Centre (the hospital's booking team) on 21 July. The referral was reviewed by a clinician who confirmed the need for an urgent appointment (defined as within six weeks). Due to lack of capacity the appointment was booked for 1 November 2016 (14 weeks later).

2.1.3 On 1 November 2016 the patient was seen by a consultant in the glaucoma clinic in the HES. It was noted in her HES records that the patient had ‘quite advanced VF [visual field] loss and disc cupping’. Her IOP was recorded as 20mmHg in both eyes. New eye drops were prescribed, and the documented plan was for follow-up in approximately four weeks’ time.

2.1.4 The patient attended her next review appointment in the glaucoma clinic on 30 November, where she was examined by a senior trainee ophthalmologist. It was noted in the clinic letter to her GP:

‘Although on drops her pressure today is better (note 9). She has some decreased visual acuity in the right eye with reduced colour vision but no RAPD (note 10). However we will do an MRI [magnetic resonance imaging scan] and bloods to exclude any other pathology in such a young person with such advanced VF [visual field] loss’.

It was also noted that since her pregnancy the previous year, the patient had been ‘bumping into things’ and that she was ‘very upset with the news that she has advanced glaucoma with significant vision loss which is not reversible’. The documented plan was for follow-up in approximately six weeks’ time.
2.1.5 On 25 January 2017 (eight weeks later) the patient was seen in the glaucoma clinic by the same senior trainee. Her IOP was documented as 14mmHg in her right eye and 15mmHg in her left eye. A new prescription for eye drops was made as the patient’s ‘eyes were quite red and corneas dry’. It was documented in her HES records that the MRI (scheduled for 26 January) and blood results were awaited (note 11). The clinic letter to the GP noted the aim ‘to get the pressure as close to 10 as possible but will review with blood results and scan. In the meantime I have registered partially sighted’. The plan was for a follow-up appointment in approximately two months’ time.

2.1.6 The MRI scan took place on 26 January 2017. This showed features consistent with advanced glaucoma but no other causes for the patient’s symptoms.

2.1.7 The patient was next seen in the glaucoma clinic on 19 September 2017 (nearly eight months later) by a specialist registrar (note 12). The registrar documented that the patient had not applied her eye drops that morning, but had said she didn’t usually forget to put them in. Her IOPs were noted to be high at 18mmHg in her right eye and 16mmHg in her left eye. It was documented in the clinic letter to the patient’s GP that surgery was discussed, and leaflets given regarding this. The plan was for follow-up in two weeks.

2.1.8 On 21 November (two months later) the patient was seen by a locum consultant in the glaucoma clinic. Her IOP was noted to be 16mmHg in her right eye and 15mmHg in her left eye. The clinic letter to the GP stated: ‘Severe loss of fibres at optic discs...Referred to [consultant A]"
for potential surgery.’ The documented plan was for follow-up in one month. The investigation found no evidence of this referral being made.

2.1.9 The patient was next seen in the glaucoma clinic, by a different locum consultant, on 31 January 2018. Her IOP was documented to be 14mmHg in her right and left eye. It was noted that the patient had been ‘having problems’ with one of her drops ‘but still uses them’. In addition, the records stated:

‘IOP borderline for her subtotal cupping, ideally should be around 9-10mmHg. Long discussion with patient, warned her she will most probably need trab [trabeculectomy (note 13] BE [both eyes]…Really worried about the risk of blindness, burst into tears while discussing the situation, re-assured her that we will do our best to retain the rest of her vision. She has noticed recently that she bumps into things more often than in the past.

Plan: see her urgently next week in [consultant A’s] clinic to decide on further Mx [management].’

2.1.10 On 6 February the patient was seen in the glaucoma clinic but initially not by consultant A as had been planned. Instead she saw another (third) different locum ophthalmologist who documented her IOP as 11mmHg in both eyes. This ophthalmologist stated in his clinic letter to the patient’s GP:

‘IOP 11/11 which is at target. Unfortunately she is gradually losing her sight and is very upset about it. We have explained [to] her that due to [the] advance[d] nature of her glaucoma slow progression is possible.
Explained that surgery carries risk of total wipe out of vision. I have requested [consultant A] for her kind opinion and she will review her today.'

Consultant A saw the patient within an hour of seeing the locum ophthalmologist (note 14). Consultant A documented the history of events so far, including the patient’s social history and personal circumstances. Consultant A recorded the patient’s IOP as 26mmHg and her impression that the patient had ‘Advanced POAG (note 15)’ and that her IOP was ‘not controlled’. She arranged for the patient to have laser surgery the following week, the choice of procedure being influenced by the fact that the patient was breastfeeding (note 16). The consultant also altered the patient’s eye drop regime and registered her as severely sight impaired. The consultant referred the patient to a sight loss advisor stating her view that, being the main carer for three very young children, the patient may need a lot of support. After reviewing the timeline of events, the consultant submitted a clinical incident report as a formal record and escalation of her concern regarding delays in the patient’s appointments which ‘may have resulted in worsening of condition (note 17)’.

2.1.11 On 13 February the patient underwent laser surgery (selective laser trabeculoplasty (note 18)) on both eyes. It was documented in the operation notes that she had a headache during the procedure but there were no other complications. Follow-up was planned in the glaucoma clinic in approximately one week’s time.
2.1.12 Consultant A reviewed the patient in the glaucoma clinic on 27 February. The patient’s IOP was documented to be 15mmHg in her right eye and 17mmHg in her left eye. The consultant noted in her clinic letter to the patient’s GP that one of the drops the patient was using caused stinging when applied so a different eye drop was prescribed. The documented plan was for follow-up in approximately six weeks’ time.

2.1.13 The patient was next seen by consultant A on 12 April. In her clinic letter to the GP the consultant stated:

‘I am delighted to say she is tolerating her drops and her pressure is much better controlled being 16 mmHg in both eyes. [The patient] is doing well and I have arranged to see her again in four months’ time.’

2.1.14 The patient was reviewed again in the glaucoma clinic on 2 August when her IOP was documented to be 19mmHg in both eyes. The documented plan was for follow-up in approximately four months’ time (December 2018).

2.1.15 The patient was next seen by consultant A on 28 February 2019 (a delay of two months from the planned follow-up date). The consultant documented: ‘visual acuity getting worse...needs probable [surgical] intervention [to] lower IOP.’ The patient’s IOP was recorded as 16mmHg in her right eye and 15mmHg in her left eye. The consultant also noted the need for a repeat MRI and blood tests to exclude any other cause for the patient’s vision loss and requested a second opinion from her colleagues regarding the best treatment plan. The appointment for this second opinion was booked for 7 March 2019.
(after the time of the Healthcare Safety Investigation Branch’s last visit to the Trust).

2.2 Impact

2.2.1 The investigation team met with the patient and her husband. They were very willing to be involved in the national investigation to help prevent “other people having this...[we] don’t want them to be a victim as we are”. They described the “catastrophic effect” of the patient’s loss of vision on their lives. She explained that her reliance on others meant “I often feel useless and struggle to cope”.

2.2.2 The patient shared many examples of the daily impact of her loss of sight on her life, such as not being able to see her children’s faces, read books to them or care for them. She and her family live in a maisonette on the third floor. The patient is unable to leave her home without someone to help her as she is unable to see the various belongings left out in the concrete communal corridors and steps, which create a trip hazard. This means the patient is confined to her flat with the children, whose toys also create a trip hazard.

2.2.3 The patient said one of the “most painful parts” of her loss of sight was her belief that her sight would have been saved if she had been listened to on the many times she recalled phoning the hospital in 2017. The patient said she told staff that her sight was worse, that she could no longer read and that she needed to see someone. She recalled being told that there were “lots in the queue” and that she needed to wait for an appointment. She felt “they don’t care”.
2.2.4 The patient’s husband explained how he had reduced his working hours so he could look after the children, and that a support worker assists on some days. In a letter to the hospital detailing her experience, the patient stated: ‘I do not feel that I will ever come to terms with what has happened to me.’

2.2.5 The Trust considered the delays in the patient’s appointments and treatment and assessed the preventability of her loss of vision. They concluded:

‘It is not clear as to the extent [the patient’s] sight has been affected by the delays. Her sight was poor prior to the delay...This delay has meant that we have missed an opportunity to preserve what sight she had at this point...The delays... have left [the patient] significantly disabled and unable to lead a normal life.’

During interview, the patient’s current consultant confirmed that, in her opinion, the patient’s disease progression would have been prevented had she been seen and treated in a timely way.

6 In 2016, opticians could not refer directly to the community ophthalmology service.
7 The GP referral was made using a national system called the e-Referral service. This service requires patients to choose and book their appointment.
8 The patient was prescribed eye drops called Latanoprost. Latanoprost eye drops increase the natural outflow of fluid from inside the eye into the bloodstream, thus reducing the pressure within the eye.
9 The patient’s IOP was 12mmHg in her right eye and 13mmHg in her left eye.
10 RAPD stands for relative afferent pupil defect. It relates to whether there are differences between a person’s eyes in how they respond to a light being shone in one eye at a time. In healthy eyes, the reaction of the pupils in the right and left eyes are linked. Testing for RAPD can be useful in detecting disease of the retina or optic nerve.

11 The usual practice is for patients to go to their GP for blood tests before the next eye unit appointment. At this clinic appointment blood was taken for testing.

12 Specialist registrars are qualified doctors who have at least four years postgraduate experience, two of which are in their chosen specialty.

13 Trabeculectomy is a surgical operation which lowers the intraocular pressure inside the eye in patients with glaucoma.

14 The exact timing is unclear. The patient stated that the locum consultant said she may have to wait an hour, but she recalled seeing consultant A sooner than this.

15 POAG stands for primary open angle glaucoma. See section 1.1.2.

16 Unlike other forms of surgery, laser surgery does not require the patient to be treated afterwards with eye drops that are toxic to living cells. Laser surgery therefore posed less risk of harm to the patient’s breastfed baby.

17 Documentation by consultant A in the patient’s eye records.

18 Selective laser trabecuoplasty is one option for lowering intraocular pressure. The trabecular meshwork is around the periphery of the eye and is where fluid formed in the eye drains out of the eye. This meshwork is treated directly with the laser to improve drainage through it.
3 Involvement of the Healthcare Safety Investigation Branch

3.1 Notification of the reference event

3.1.1 Lack of timely monitoring of patients with glaucoma was identified by Healthcare Safety Investigation Branch (HSIB) as a patient safety risk priority for investigation. This patient’s experience (the reference event) was referred to HSIB by the legal representative dealing with the 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 (the Strategic Executive Information System (StEIS) (note 19)). HSIB contacted the Trust and a 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’s involvement and collaborated with information gathering.

3.2 Decision to investigate

3.2.1 Following scoping, HSIB’s Chief Investigator authorised a full investigation based on HSIB’s patient safety risk criteria:

Outcome impact – what was, or is, the impact of the safety issue on people and services across the healthcare system?

3.2.2 Lack of timely monitoring of patients with glaucoma can cause premature sight loss and blindness. Loss of vision can significantly affect a person’s mental and
physical health. For example, it can course depression and lead to falls with resulting injuries such as hip and knee fractures.

3.2.3 The quality and reliability of ophthalmology services are affected by the services’ inability to monitor and control appointment backlogs.

3.2.4 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.

Systemic risk – how widespread and how common a safety issue is this across the healthcare system?

3.2.5 The safety risk has a wide geographic spread reflecting the systemic nature of the issue. An initial search of StEIS identified 158 incidents reported as occurring 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). Eighteen of these reports related to groups of patients and/or incidents; the exact number of patients affected was not given. A further review on StEIS, of the same time period, analysed reported incidents specifically involving glaucoma outpatient follow-up, looking at identified 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). Appendix A shows the search criteria used for the review.

3.2.6 In April 2009 the National Institute for Health and Care Excellence (NICE) released guidelines for the assessment and treatment of glaucoma including standards for follow-up [8]. To complement these guidelines, the National Patient Safety Agency (NPSA) published a Rapid Response Report [9]. The report detailed incidents resulting in harm and made a number of recommendations to prevent delayed follow-up of patients with glaucoma. The recommendations were directed at ophthalmology services and organisations that commissioned ophthalmology services. Despite these guidelines and recommendations, lack of timely monitoring of patients with glaucoma has persisted as a patient safety risk.

3.2.7 The British Ophthalmological Surveillance Unit (BOSU) found that up to 22 people per month were experiencing permanent and severe vision loss due to health service-initiated delays [11].

3.2.8 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 (note 20) and the number of patients seen is increasing. The 2018 report by the All-Party Parliamentary Group on Eye Health and
Visual Impairment [10] 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.’ The 2018 workforce census by the Royal College of Ophthalmologists found there was an inadequate ophthalmic workforce and based on current ways of working ‘the data suggests an extra 230 consultant posts are required to meet the rising demand for ophthalmology services over the next two years’ [14].

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

3.2.9 Despite recognition that the lack of timely follow-up increases the risk of sight loss, and recommendations being made to address it almost 10 years ago, the risk has remained. This suggests there are complexities associated with implementing the recommendations that need to be understood and acknowledged.

3.2.10 A safety investigation can provide a ‘deep dive’ into the issue and insight into why systems cannot control the problem.

3.2.11 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.

3.3 Focus of investigation

Following the scoping exercise, it was agreed that the national investigation would:
• analyse the reference event to understand the context and contributory factors
• review the national context surrounding delays in the monitoring of patients with glaucoma
• assess the adequacy of the risk controls in place to mitigate the safety risk to patients and identify where opportunities for error remain
• develop safety recommendations to reduce the risk of patients with glaucoma not being monitored in a timely way.

3.4 Evidence gathering and investigation process

Evidence

3.4.1 Evidence gathered in this investigation included:
• review of the patient’s clinical records, and policies, procedures and practice in place at the Trust where the reference event occurred regarding follow-up and appointment booking for patients with glaucoma
• interview and telephone conversations with the patient
• interviews with 11 staff at the Trust
• observations of the booking process at the Trust to understand the complexities of the task
• review of the Trust’s internal serious incident investigation report
• search of StEIS between 1 April 2017 and 31 December 2018 (20 months) using the
search term ‘glaucoma’ for reported incidents which involved outpatient follow-up

- review of literature relevant to the safety risk
- consideration of information submitted to HSIB (note 21) by the Association of Optometrists and Local Optical Committee Support Unit (note 22)
- interviews in person and by telephone with representatives of relevant national organisations (note 23), subject matter advisers (note 24), and members of the Royal College of Ophthalmologists Clinical Leads Forum, regarding the follow-up of patients with glaucoma and possible improvements to reduce the safety risk
- interviews with patients affected by glaucoma regarding their experiences (note 25)
- interviews with seven trust clinical leads to discuss their risk management processes and changes in ways of working.

**Investigation process**

3.4.2 The investigation used the terms and definitions below which are taken from the Australian Transport Safety Bureau’s Safety Investigation Guidelines Manual [15]:

- A safety factor ‘is an event or condition that increases safety risk’.
- A safety issue is a safety factor that ‘is a characteristic of an organisation or a system, rather than a characteristic of a
specific individual, or...environment at a specific point in time. Safety issues will usually refer to problems with...risk controls’.

- Risk controls are ‘measures put in place to facilitate and assure safe performance of the operational components of the system’.

- Preventative risk controls are measures put in place to reduce the likelihood of adverse events.

- Recovery risk controls are measures put in place to detect and correct adverse events.

3.4.3 HSIB uses a standard process in all its investigations which may be supplemented by additional steps specific to the event under investigation. The process is as follows:

- gather all relevant evidence
- establish the factual circumstances leading up to the reference event
- analyse the evidence
- identify the most significant safety factors and safety issues contributing to the safety risk being investigated
- identify which safety factors are contributory to the reference event
- identify which safety issues are likely to contribute to future, similar events nationally - these inform the wider investigation (see section 5)
- assess the adequacy of risk controls in place
• develop safety recommendations and safety observations to reduce identified safety risk.

3.4.4 During the analysis of investigation findings, systems diagrams were used to illuminate the dynamics of the ophthalmology and wider healthcare system [16]. Accimap [17] and a control structure diagram from the Causal Analysis using Systems Theory (CAST) approach [18] were used as diagramming techniques. Both approaches considered the vertical interaction among levels of a sociotechnical system, as illustrated in Figure 2. This encompasses decision making through the levels of management and governance, as well as economic considerations and workload pressures [17]. The AcciMap approach was used to facilitate an ideation session with the investigation team, whereas the control structure diagram was used to represent control-feedback loops across system levels.
Fig 2 A simplified generic AcciMap example (adapted from Svedung and Rasmussen, 2002 [19])

1 Government, policy & budgeting

2 Regulatory bodies and associations

3 Local area government, Company management, Planning and budgeting

4 Technical and operational management

5 Physical processes and actor activities

6 Equipment and surroundings

Policy → Regulations → Staffing and resources → Planning

Planning criteria → Company policy

Resourcing and staffing

Consequence
19  All reported clinical incidents are submitted by trusts to StEIS. Incidents that are considered serious incidents, which includes those resulting in permanent harm or death, should also be recorded on StEIS. This system facilitates the monitoring of investigations between NHS providers and commissioners. A full list of incidents defined as serious can be found in the Serious Incident Framework: 
https://improvement.nhs.uk/resources/serious-incident-framework/

20  This is based on hospital episode data for 2017/18 (the latest available):

21  The Association of Optometrists and Local Optical Committee Support Unit submitted information to help inform the investigation following the publication of the Interim Bulletin on HSIB’s website.

22  The Association of Optometrists is a membership body for optometrists and other eye health professionals. The Local Optical Committee Support Unit provides practical support to local optical committees in England to help them develop, negotiate and implement local objectives in respect of primary ophthalmic services.

23  For example, the Royal College of Ophthalmologists, the International Glaucoma Association, NHS England/Improvement, and the Getting It Right First Time (GIRFT) programme.

24  The subject matter advisors included the Chair of Professional Standards for the Royal College of Ophthalmologists; the joint clinical leads and Clinical Advisor for the GIRFT ophthalmology programme; the Director of the National Elective Care Transformation Programme; and the Pricing Regulation Lead for NHS England/Improvement.

25  Interviews were arranged through the Royal National Institute of Blind People and the International Glaucoma Association.
4 Findings and analysis at the hospital where the reference event occurred

In order to identify the safety factors, safety issues and local risk controls, the investigation reviewed the patient’s clinical records and interviewed frontline staff and managers at the Trust where the reference event occurred. In addition, Trust policies and national guidance were reviewed to determine whether actions taken in the reference event aligned with them.

4.1 Booking process

4.1.1 At the Trust, booking of appointments is carried out by a centralised booking team, the Patient Services Centre (PSC). Within the PSC, staff are assigned to book appointments for particular specialties; hence there is a team dedicated to ophthalmology. There are standard operating procedures to guide staff through the processes involved.

4.1.2 The PSC Deputy Team Leader (note 26) and the Operations Co-ordinator informed the investigation about the process for booking ophthalmology appointments (Figure 3 and Figure 4). The investigation also observed the booking process in action.

4.1.3 When a patient is referred to the hospital eye service (HES), the referral form and accompanying referral letter (from the referring clinician, with details of the reason for referral and other clinical details) is sent to the PSC. The PSC date-
stamps the referral form and completes information required to monitor the 18-week pathway (note 27) [20]. The PSC sends the referral letter for ophthalmology review and a decision regarding how soon the patient needs to be seen for their first appointment. This decision is communicated to the PSC by completion of a ‘grading slip’.

4.1.4 The PSC then accesses the electronic clinic diaries on the patient administration system (eCamis) to make an appointment in the requested timeframe. If there is no availability in the requested timeframe, the PSC books the patient into the next available slot. However, the Deputy Team Leader said that the PSC will escalate the need for an appointment to the Operations Co-ordinator or Access Manager if a patient has been requested to be seen within a few weeks and this timeframe cannot be met – that is, they have been graded as a ‘Priority’ (appointment within two weeks) or ‘Urgent’ (appointment within six weeks) on the grading slip. If an appointment cannot be found, the patient would be given the first available slot and added to a capacity database specifically for first appointments that are outside the requested timeframe. The Deputy PSC Manager and members of the Divisional Management Team said there was much less capacity for follow-up appointments than first appointments.

4.1.5 If a follow-up appointment is required, the ophthalmologist completes a form known as a ‘routing slip’ after seeing
the patient in clinic. The front page of
the form includes details regarding the
consultation. The back page has details
of the outcome of the appointment,
including follow-up arrangements. The
routing slips are collected at the end of
clinic by a member of the PSC.

4.1.6 To book a follow-up appointment, the
PSC follows the same process as for a
first appointment except that they will
look for a slot with the ophthalmologist
the patient has seen. If there is no
available appointment, and follow-up
has not been requested within three
weeks (that is, it is not an urgent follow-
up) the PSC books the patient into the
next available clinic slot (which may be
months after the requested timeframe)
and adds the patient's name to a follow-
up capacity database.

4.1.7 The Operations Co-ordinator explained that
the reason for booking an appointment,
even though it may be months beyond
the requested timeframe, was to
minimise the risk of the patient getting
lost in the system and to ensure they
at least had an appointment to be
seen again. The practice therefore
acts as a preventive risk control (see
3.4.2). The database includes the
appointment timeframe requested and
the appointment date actually given. If
an earlier appointment is subsequently
found for the patient, or if they attend
and are seen for some other reason, the
database should be updated.

4.1.8 The Deputy Team Leader told the
investigation that when follow-up
appointments are requested within
three weeks of the patient initially
being seen in clinic (‘urgent’ follow-up) the Operations Co-ordinator is contacted by the PSC booking team if no available clinic appointment can be found. The Co-ordinator then liaises with the ophthalmologists to create an appointment within the timeframe, for example, by extending a clinic. This, therefore, acts as a recovery risk control (see 3.4.2).

4.1.9 The Operations Co-ordinator was based in the HES and had easy access to, and long-standing working relationships with, the consultants. Furthermore, she previously worked in the PSC and had many years’ experience of the ophthalmology service and clinic booking so was able to navigate the booking system with ease. She pointed out the idiosyncrasies of the IT booking system – for example, when looking to book a patient’s next appointment, the system will default to the next available appointment with the ophthalmologist the patient has just seen, rather than the next available slot with any ophthalmologist. She explained the different possible on-screen views of diary availability and the benefits of detailed knowledge of the different clinics and ophthalmologists which meant she could make a judgement about where extra capacity may be created, and who would be able to see the patient based on their particular areas of expertise. On receipt of emails each day about the need for urgent appointments, the Co-ordinator would liaise with the consultants as needed and identify a clinic the patient could be booked into (sometimes meaning the clinic is overbooked).
**Fig 3** Booking process for first appointments in the eye unit following referral from the community

- **Patient seen in community and referral made to eye unit**

- **Referral received by patient services centre**

- **Referral sent for clinical decision regarding level of priority and timeframe within which patient needs to be seen**

- **Decision communicated to patient services centre via the grading slip**

  - **Yes**
    - Patient appointment available in requested time frame
      - Appointment booked and patient informed by letter
  
  - **No**
    - Patient booked into next available appointment and informed by letter. Patient added to capacity database
 Booking process for follow-up appointments

1. Patient seen in outpatient department and doctor requests a follow-up appointment on the routing slip.
2. Routing slips collected at the end of the clinic by patient services centre staff.
3. Patient services centre codes the clinic episode and accesses clinic diary to look for appointment in requested timeframe.
4. If yes, patient appointment available in requested timeframe.
   - Yes: Appointment made in requested timeframe and patient informed by letter.
   - No: Appointment requested in 1-3 weeks? (Urgent)
     - Yes: Patient services centre emails operations co-ordinator who liaises with consultants and identifies slot for appointment.
     - No: 

Fig 4 continued on next page
Patient services centre emails operations co-ordinator who liaises with consultants and identifies slot for appointment.

Operations co-ordinator emails patient services centre with directions about which clinic to book patient into.

Patient services centre books next available appointment. Patient is informed by letter. Patient is added to capacity database.

Capacity database is validated by operations co-ordinator every 3-6 months.
4.1.10 The Deputy PSC Manager explained that booking follow-up ophthalmology appointments is more complex and time-consuming than many other specialties as patients often require appointments for visual field tests that need to be coordinated with the appointment. She commented on the pressures within the entire PSC; its staff respond to several hundred patient calls per day as well as booking appointments across all specialties. The investigation reviewed two random days’ calls into the PSC (a Tuesday and a Wednesday). On both days approximately 20% of calls were related to ophthalmology. It was not possible to identify from the data how many calls concerned appointments. The Deputy PSC Manager noted the difficult position staff are in as they “want to help patients but are unable to find appointments for them”. She also pointed out the fast turnover of booking staff and the training required for new staff.

4.1.11 The number of calls from ophthalmology patients into the PSC has risen each year (Figure 5). The Deputy Team Leader said that “most of” the phone calls from ophthalmology patients are about delays in appointments. She said sometimes the PSC would receive “three or four calls by the same patient the same day asking if there had been any cancellations”. Staff are expected to fill in an activity code related to the reason for each call. The investigation team visited the Trust (in February and March 2019) and reviewed the calls received in one day (note 28). There were 965 calls into the PSC of which 180 (18.65%) were from ophthalmology patients. The activity code was not completed for
Fig 5  Number of calls per month received by the PSC from April 2013 - February 2019

PSC INBOUND OPHTALMOLOGY CALL VOLUMES

LINEAR TREND LINE
60% of these calls. Of the completed codes, just over 50% were queries about appointments or capacity.

4.1.12 In the reference event, the community ophthalmology service referred the patient to see an ophthalmologist at the HES on 20 July 2016. The referral was sent with a letter addressed to consultant A requesting an ‘urgent assessment’. However, usual practice was for all referral letters to be reviewed by the ophthalmology team who would then decide how soon, and by whom, the patient should be seen. The referral was stamped as received by the PSC on 21 July. Usual practice was followed, and the decision was communicated to the PSC by completion of a grading slip. The referral was reviewed by a glaucoma clinical fellow (note 29) and the grading slip completed on 1 August 2016. The grading slip requested that the patient be seen urgently in consultant A’s glaucoma clinic. For booking purposes, and in accordance with NHS referral processes, ‘urgent’ is defined as an appointment within six weeks. So, the request was for the patient to be given an appointment by 12 September. Consultant A told the investigation that she may have been on holiday at the time of the referral and thus a colleague reviewed it. She said the request for an urgent appointment was appropriate – National Institute for Health and Care Excellence (NICE) guidance confirms this [8].

4.1.14 Due to the lack of capacity, the patient’s first appointment was booked for 1 November 2016 (13 weeks later) and was not in consultant A’s clinic as requested. Consultant A told the investigation that
her clinics are always full, so the patient may have been booked into another consultant’s clinic because it had the first available appointment. The Operations Co-ordinator said that consultant A has only four new patient appointment slots per week (the majority of appointments being for follow-ups, where the need for capacity is greatest) so it was likely that, after checking with an ophthalmologist, the PSC was advised to book the patient into another consultant’s clinic.

4.1.15 The Deputy Team Leader for the PSC said that if a patient’s first appointment is not found within the requested timeframe, the next available appointment is booked, and they are added to a capacity database. It was not possible to confirm if this happened in relation to the patient in the reference event as the database has been updated since that time.

4.1.16 The patient told the investigation that she had telephoned the HES on repeated occasions during 2017 when she was aware her sight was deteriorating. She recalled asking for an appointment to ‘see a consultant urgently...as I felt my vision was getting worse; I had now started bumping into things’. She said she was told there were ‘many people on the waiting list and...that I needed to wait for an appointment’. The Trust’s call management system retains a call history for 465 days and a recording of calls for one year from the date of the call. Therefore, when the investigation visited the Trust on 6 March 2019, the call history...
was only available from 20 November 2017 (after the period of the most significant delay) and no phone recordings from 2017 were available.

**Summary**

4.1.17 Ophthalmology appointments are booked by a centralised booking team. There are standard operating procedures to guide staff through the process of booking appointments and adding patients to the follow-up capacity database.

4.1.18 Booking ophthalmology appointments is a skilled task. The staff who do this are also responding to multiple calls from patients concerned about appointment delays. The lack of capacity adds to staff pressures.

4.1.19 In the reference event, the patient’s referral was graded by an ophthalmologist at the HES as requiring an appointment booked within six weeks. Due to lack of capacity the appointment she was given was in 13 weeks’ time.

### 4.2 Insufficient capacity to meet demand

4.2.1 All staff interviewed at the Trust commented on the sustained pressure on the ophthalmology service, which the Divisional Clinical Lead (note 30) described as “working beyond capacity”. As a result, a significant backlog of patients awaiting appointments built up over a number of years, primarily in three lifelong conditions: diabetic retinopathy (note 31), age-related macular degeneration (note 32) and glaucoma.

4.2.2 The Trust’s serious incident report, Delayed follow ups for Glaucoma Patients, dated June 2018, identified...
4,500 patients who needed an appointment who could not be offered one within the appropriate timeframe. The report noted that that the ophthalmology service had been running beyond maximum clinic capacity, with clinics being overbooked by about 15%. This 15% consisted of patients referred from other areas such as the emergency department. They were patients whom clinicians had agreed to see as ‘extras’ in their clinics because of their high risk of vision loss. The Trust’s investigation report estimated it would take 18 months to see all the ophthalmology patients in the backlog. It stated that 16 patients had suffered harm and required urgent treatment (one of whom was the subject of the reference event in this investigation).

4.2.3 The Trust’s serious incident report estimated that the deficit of follow-up appointments per month was 670.

This figure was based on the number of patients added to the capacity database because there was no available appointment in the specified timeframe. The Care Group Management Team (note 33) informed the investigation that a review of the capacity database carried out in early February 2019 showed the deficit of follow-up appointments was 545.

4.2.4 The Trust holds extra clinics as one way of creating additional capacity. This will often involve weekend working or amendment of a consultant’s work schedule. When the investigation visited the Trust in March 2019, additional clinics had been arranged for the three consultants who specialise in glaucoma (one of whom is consultant A). The clinics were for the group of patients for whom follow-ups had been requested.
within four months, but who were on the capacity database as an appointment had not been found within this timescale. Consultant A had 512 such patients. Three extra clinics had been organised of 12 slots, thereby reducing the backlog by 36 appointments. Another of the glaucoma consultants had 1,083 such patients and six extra clinics had been organised, providing 72 slots. The next available follow-up slot in a routine clinic was in 2020. As these numbers demonstrate, and as staff are well aware, the provision of extra clinics without a significant expansion in workforce is an inadequate risk control.

4.2.5 Consultant A and the Divisional and Care Group Management Teams told the investigation that workforce issues had compounded the shortage of capacity. They stated that medical staff numbers had not increased to match the rise in demand for glaucoma treatment and care. At the time of release of the Trust’s investigation report in June 2018, one consultant post, one senior fellow post and two nurse practitioner posts were vacant. When the investigation visited the Trust (February 2019) the consultant and clinical fellow posts had been filled and a further consultant post was being created. One nurse practitioner post had been filled.

4.2.6 The Medical Director of the Trust where the reference event took place informed the investigation of another local circumstance that he thought had affected the ability to recruit consultants. This safety factor was the commissioning arrangements, which he described as “fragmenting” ophthalmology services.
He explained that the Trust was one of four providers, the others being in the private sector. He said the Trust dealt with complex cases where patients required long-term follow-up. The other providers saw uncomplicated cases and carried out high-volume, quick surgery, such as cataract operations. He said this meant the Trust was carrying out less profitable, more complex work with very few surgical sessions in consultant job plans. The Medical Director and Divisional Management Team said that the lack of surgical time in particular made posts unattractive to consultants. The Trust’s inability to meet waiting times for cataract surgery (due to both staffing and eye operating theatre capacity) made it essential to have alternative providers. The Senior Commissioning Manager noted that one possibility might be to work collaboratively by having joint posts across providers. The Senior Commissioning Manager said that as a tertiary (specialist) HES and teaching hospital, the biggest volume of work will be with patients who have complex cases and who need the expert input only the HES can provide.

The investigation interviewed the Senior Commissioning Manager and the Quality Lead for ophthalmology from one of the local commissioning groups. Commenting on the concern about fragmentation of services, they said the

4.2.7

4.2.8

The problems with recruitment meant the Trust had to employ locum ophthalmologists to enable clinics to run. The investigation was informed that the locums had different levels of
knowledge and skill and lacked the permanent staff’s knowledge of local procedures and practices. The Care Group Management Team described an “instability in the system” that had resulted from frequent changes in locum staff.

4.2.9 Consultant A and the Divisional Management Team stated that the lack of physical space within the ophthalmology outpatient department was a further factor compounding the capacity issues, and that it limited opportunities for different ways of working. Consultant A advised the investigation that there were 16 cubicles in the outpatient area and 22 consultant ophthalmologists (three of whom specialised in glaucoma). The Trust had identified theatre and outpatient space at another of their hospital sites (acquired in 2017) which would allow a limited increase in service expansion within the constraints of staffing capacity.

4.2.10 Consultant A and the Divisional and Care Group Management Teams all pointed out the recognition (both locally and nationally) of the need to find ways to safely monitor and manage patients with glaucoma that was not so reliant on consultant ophthalmologists. The Medical Director and Divisional Management Team informed the investigation of discussions that had taken place with commissioners about ways of creating capacity to meet demand.

4.2.11 One option that had been discussed was discharging patients at low risk of sight loss to be managed by
ophthalmology services outside the HES, thus relieving pressure. The Divisional and Care Group Management Teams noted that they saw patients from a geographical area covered by two clinical commissioning groups (CCGs). One of the CCGs (representatives from which the investigation interviewed) had commissioned an ophthalmology service run by a retired consultant ophthalmologist and GPs with a special interest in ophthalmology.

4.2.12 The Divisional Management Team said a further option discussed was for patients suspected of having glaucoma by standard opticians to be re-examined by primary care optometrists, to determine whether referral to the HES was required. Team members said there had also been consideration of a commissioned optometrist-led service for monitoring of low-risk patients with glaucoma. However, they pointed out that optometrists need to have a particular level of knowledge and training to monitor patients with glaucoma and upskilling this staff group to the necessary level meant “it was not a quick win”. In addition, the team members thought there may be difficulties in attracting optometrists to this role given that the pressure of work was likely to be greater, and the pay less, than they may receive in high-street opticians.

Representatives from the CCG said this option was being pursued by the other CCG that commissioned services from the Trust. They noted that this was to be an interim measure while a community ophthalmology service was set up,
mirroring the one commissioned by their CCG.

4.2.14 The Divisional and Care Group Management Teams said the majority of patients being seen by the HES were at high risk of vision loss so the provision of alternative services for low-risk and stable patients had limited impact on their patient caseload. CCG representatives pointed out that, while limited, it was not insignificant. For example, they reported that a review of patients referred to the community ophthalmology service from opticians found that 30% were referred on to the HES, with 70% being managed or discharged by community services. Furthermore, a review of 100 HES patients in the catchment area for the existing community ophthalmology service identified 73 as high risk and needing the specialist input of the HES but 27 who could be discharged to the care of the community service.

4.2.15 Consultant A and the Care Group Management Team told the investigation that nurse practitioners could manage some aspects of care, with consultant oversight. That said, they emphasised the need for investment in training and development, with career progression, in order to retain these staff.

4.2.16 The Divisional Management Team said they were also considering other options such as virtual clinics. In these clinics consultants do not physically see patients but review their recent eye test results. Thus, more patients can be assessed than in a face-to-face clinic. Patients are then contacted with the review outcome (see 5.1.32 to 5.1.36).
4.2.17 The Care Group Management Team’s Clinical Lead told the investigation of influences both within the Trust and in the wider healthcare system that were relevant to the issue of capacity in the management of glaucoma. He pointed out that the HES was based in an acute Trust where the focus was on acute illness rather than chronic (long-term) disease management of conditions such as glaucoma. The Clinical Lead said that the financial tariff for seeing a patient for a follow-up appointment was less than that for seeing a new patient, which resulted in a general organisational focus on reducing the ratio of follow-up to new patients. He pointed out that this was not possible for patients with glaucoma, where the majority would be on long-term follow-up after diagnosis, with a very low discharge rate.

4.2.18 A further safety issue highlighted by the Clinical Lead was the slow, progressive nature of the condition for the majority of patients in England, which meant they did not chase appointments in the way they would for a condition where deterioration was more obvious. He pointed out that in people of African origin the disease was more likely to progress, which added urgency in the case of the patient involved in the reference event. The CCG Senior Commissioning Manager pointed out the lack of general public awareness of the importance of eye health, and the benefits of having eye checks every one to two years, depending on age and risk factors (note 34).

4.2.19 The Care Group Management Team Operations Manager said that the issue of insufficient capacity to meet demand
had been on the Trust’s risk register since 2014. However, he noted that the level of priority assigned to the issue had fluctuated over time, and at one point it had become amalgamated with the lack of physical space within the ophthalmology outpatient area.

4.2.20 The investigation reviewed the timeline of the patient’s appointments with consultant A (the patient’s current consultant). The consultant said that, in her opinion, the requested appointment follow-up timeframes were reasonable up to the patient’s appointment with a locum consultant on 21 November 2017. At this appointment, the consultant said she would have expected the locum to escalate the case and discuss it directly with her. Had this occurred the consultant thought she would have requested review in two weeks rather than one month. The patient’s care was directly discussed with the consultant after her next appointment on 31 January 2018. Laser surgery was then organised and performed the following week (6 February 2018). The consultant confirmed that subsequent appointments were requested at appropriate timeframes.

4.2.21 The investigation considered the requested follow-up times against the NICE guidelines [8]. For people diagnosed with chronic open angle glaucoma (COAG), these state: ‘Use clinical judgement to assess risk of COAG progression to sight loss, and reassess according to [intervals set out].’ An important factor in determining the reassessment interval is whether the intraocular pressure (IOP) is controlled (Table 1).
### Table 1 Time to next assessment for people with COAG

<table>
<thead>
<tr>
<th>Progression of COAG</th>
<th>Control of IOP</th>
<th>Time to next assessment (note 1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not detected</td>
<td>No</td>
<td>Review treatment plan and reassess between 1 and 4 months</td>
</tr>
<tr>
<td>Uncertain progression (note 2) or progression</td>
<td>No</td>
<td>Review treatment plan and reassess between 1 and 2 months</td>
</tr>
<tr>
<td>No progression detected and low clinical risk</td>
<td>Yes</td>
<td>Reassess between 12 and 18 months</td>
</tr>
<tr>
<td>No progression detected and high clinical risk</td>
<td>Yes</td>
<td>Reassess between 6 and 12 months</td>
</tr>
<tr>
<td>Uncertain progression (note 2) detected and high clinical risk</td>
<td>Yes</td>
<td>Review treatment plan and reassess between 2 and 6 months</td>
</tr>
</tbody>
</table>

1 Use clinical judgement to decide when the next appointment should take place within the recommended interval.
2 Uncertain progression includes having insufficient accurate information (perhaps because the person was unable to participate in the assessment).
4.2.22 The patient’s requested follow-up was in line with NICE guidance. From the patient’s first appointment in the HES until April 2018, her requested reassessment interval was at the most frequent monitoring interval – that is, for reassessment between one and two months. At her appointment on 12 April 2018 her IOP was documented to be much better controlled and her follow-up interval then extended to four months (earlier than the six to 12 months suggested by the guidelines).

4.2.23 Due to the HES’s capacity issues, the patient was not seen in the requested timeframes. Up to February 2018, when the patient was registered as severely sight impaired, the overall delay from the time of her referral to the HES was 11 months (48 weeks). Consultant A said this meant an opportunity to preserve the patient’s already limited vision was lost. In her opinion, the patient’s disease progression could have been prevented had she been seen in the requested timeframes.

4.2.24 The situation created for patients and staff by the lack of capacity was summed up by consultant A who said: “It is so difficult trying to do your best for patients with such limited resources.”

Summary

4.2.25 There is insufficient capacity to meet the demand for glaucoma follow-up appointments. At the reference event HES a backlog of thousands of appointments built up over a number of years. Lack of ophthalmology capacity
is a recognised safety issue and a contributor to the reference event.

4.2.26 A number of local safety factors compounded the Trust’s capacity problem. These included recruitment of consultants, lack of physical space, and a lack of commissioned community services where patients at low-risk of loss of vision could be discharged for ongoing monitoring and management. There was also the safety issue of a lower tariff for follow-up appointments leading to a focus on reducing the ratio of new to follow-up appointments, which is not possible in this patient group.

4.2.27 The Care Group and Divisional Management Teams have explored new ways of working, in discussion with their commissioners.

4.2.28 The patient’s follow-up appointments were requested in accordance with the timeframes set out in the NICE guidelines. Lack of capacity meant they were not booked in this timeframe.

4.3 Management of capacity issues

4.3.1 The Trust’s serious incident report, Delayed follow ups for Glaucoma Patients, stated that: ‘Increasing risk of issues with capacity was not recognised and highlighted early enough.’ The contributory factors in the report included:

- ‘There was no escalation by Patient Service Centre of the increased waits for appointments.’
- ‘Failure of both the Patient Service Centre and Care Group Management team to validate and manage the spreadsheet..."
of patients on a regular basis as it had become too large to manage effectively.’

• ‘Ineffective collaborative working between the Care Group Management Team and Patient Service Centre.’

• ‘Inadequate Care Group Management Team oversight of the developing situation.’

4.3.2 Evidence gathered by the investigation suggested there was a good, collaborative working relationship between the Care Group Management Team and the PSC. Evidence gathered from interviews indicated the increased wait for appointments was escalated by the PSC. The PSC Deputy Team Leader, who had been in post three years, described having weekly meetings with the Operations Co-ordinator and Access Manager, who were the representatives of the Care Group Management Team that they linked with day to day. She said they were very aware of the increasing capacity problems with follow-up as they were the ones who had to find appointments for patients needing them in less than three weeks. The Deputy Team Leader said she felt very comfortable about raising issues and described the weekly meetings as “very supportive”. Again, the fact that the Operations Co-ordinator had worked in the PSC was cited as being very helpful as she had personal, detailed knowledge of “how difficult and intense” it was. These comments were echoed in the interview with the Operations Co-ordinator.

4.3.3 The PSC Deputy Team Leader, Operations Co-ordinator and Care Group Management Team Operations Manager told the investigation that the numbers of patients
on the follow-up capacity database had grown rapidly since 2016. In 2016 the number of glaucoma patients on the database was estimated to be 1,000. The provision of extra clinics was said to have brought the number down to about 500. But this risk control measure had a temporary effect in managing the capacity problem and the number rapidly grew again. By 2018 the number of glaucoma patients on the database was estimated to be 3,000. When the investigation visited the Trust on 6 March 2019 the number of glaucoma patients on the database was 3,859.

4.3.4 The Care Group Management Team Operations Manager reflected on the team’s oversight of the capacity database over the last few years and the description of this as ‘ineffective’ in the Trust’s serious incident report. He thought there had not been a lack of oversight as such (it had been on the risk register since 2014) but more a lack of appreciation of the rate of growth and the speed with which it would become out of control: “[The numbers] suddenly exponentially went from here to happened...no one sat and did the projections.” He recalled the previous Care Group Manager (note 35) asking for the numbers on the follow-up capacity database every two weeks. He said this data was escalated to the Divisional Team and from there it would be escalated to the Executive Team.

4.3.5 The Care Group Management Team told the investigation that amendments to the electronic clinical information system has enabled more meaningful oversight.
For example, all glaucoma patients have been reviewed and stratified according to their risk of vision loss. The risk stratification has given the team a much better understanding of the risk of harm and appointments can be prioritised for patients at high risk. The changes have meant the Care Group Management Team can generate reports of time intervals between intended follow-ups against booked follow-ups, giving them more nuanced data upon which to base projections and measure the success of any interventions directed at the capacity issue.

4.3.6 While changes to IT systems have brought significant benefits, the investigation was told of some challenges that remain. The Deputy Team Leader, echoing comments by the Operations Co-ordinator, showed the investigation different searches possible on the booking system and the different results yielded regarding appointment availability. Some staff had access to a previous version of the booking system which was reported as providing quicker, easier searches (in fewer mouse clicks) for available appointments than the newer version. The investigation observed the Deputy Team Leader searching for an available appointment. On the older version, available appointment slots showed up in one mouse click. On the new version, if a clinic had been overbooked but an appointment had been cancelled, this would not show up as the clinic would still be deemed full. Staff would need to know to search for ‘overbooked clinics’ or go into each clinic individually to see if there was a cancelled slot.
4.3.7 PSC staff are expected to update the follow-up capacity database after every appointment booking. Due to workload pressures such as the volume of phone calls and slow functioning of the database (screens often freeze) this does not consistently happen. This resulted in the need for a data cleansing exercise known as validation. Validation involves updating the database en masse, removing details of patients who no longer need an appointment, removing duplicate patient details and making other corrections as needed. The Operations Co-ordinator said that validation often resulted in removing the details of 300 to 400 patients from the database, which reflected the poor data quality.

4.3.8 The PSC Deputy Team Leader said that validation was originally part of the PSC’s remit but it had become impossible to do within their workload, particularly as the volume of phone calls increased. In addition, validating the database required in-depth knowledge of the patient administration and booking system, so the task could not be given to a junior or new member of staff without senior support being available. Rapid turnover within the PSC meant there was a limited number of staff who could do this. The Deputy Team Leader pointed out that the ideal would be for the booking system to link with, and automatically update, the validation database.

4.3.9 The Operations Co-ordinator told the investigation that since March 2017 she, with the support of colleagues, had started helping with the validation
of the follow-up capacity database. She explained that the validation was intended to be three-monthly, but the size of the database (which contains thousands of patient records), and therefore the time needed for the task, meant that it was not possible to undertake it more frequently than every six months.

4.3.10 The Care Group Management Team explained that validation was important to provide an accurate picture of the scale of the capacity issue and allow reliable projections regarding capacity and demand to be made.

4.3.11 The Trust’s investigation report stated that there was ‘a lack of understanding of the risk within the organisation’. The Medical Director told the investigation that while there was knowledge of the capacity issue, there was not an awareness of “the scale of the problem [or] the risk of harm”. He said the intelligence was “too soft to recognise the problem”. A critical component of this was the monitoring systems, or reports generated, which did not contain essential information such as a patient’s risk of vision loss or a comparison between their requested and actual follow-up appointment dates. The Medical Director summed up the situation by saying they became aware of the scale of the problem and risk of harm “because of incidents rather than our systems highlighting the problem to us”.

4.3.12 The Medical Director echoed comments made by the Care Group Management
Team regarding the review and risk stratification of patients with glaucoma and amendments to the clinical information system. These changes mean data is now available to allow meaningful oversight of and insight into capacity and prioritisation of appointments.

4.3.13 Comments by the CCG Senior Commissioning Manager and the Quality Lead for ophthalmology reflected those of the Medical Director and the Care Group Management Team about the lack of appreciation of the scale of the problem and risk of harm. Although there had been regular meetings between commissioners and the Care Group Management Team, it was only when specific incidents of harm were investigated that there was a realisation of the true nature of the safety risk. Like staff interviewed in the Trust, the CCG representatives reported being aware of concerns about capacity since 2014, and “heard anecdotes” of people waiting a long time for follow-up appointments, but the situation became “normalised...[the issue] needed to be higher on people’s agenda”. This normalisation occurred within a national context where the pressures on ophthalmology services were well known but there “was no national message” of how to address the problem. Reflecting on what had happened, the Senior Commissioning Manager said there was “lots to be learned about early warnings and the response to them (note 36)”.

4.3.14 The CCG Senior Commissioning Manager endorsed comments made by the Medical Director and Care Group Management Team about the role of IT
Manager spoke about the focus on metrics “at the front end”, that is, compliance with the national 18-week target. In comparison, she said there had been little attention given to numbers of follow-up appointments being given within the requested timescale. The Manager said she thought a national requirement to routinely report these numbers, as recommended by the All-Party Parliamentary Group on Eye Health and Visual Impairment [10], would be helpful in focusing attention on this safety issue. She noted that the Trust’s compliance with the 18-week target had always been good, which perhaps gave false reassurance about how the service was performing. Furthermore, the Manager noted that the patient administration system was set up to allow easy reporting of data regarding

4.3.15 In addition to the importance of system design, the CCG Senior Commissioning Manager said that ideally system design would make it possible to see the status of a service “at a glance” without needing to delve into the detail. The systems used at the time of the reference event did not allow this insight into operational pressures and level of harm patients were exposed to. The Manager commented on the value of the ophthalmology High Impact Interventions published by NHS England (note 37) [12]; she described its three recommended actions (see 4.3.21) as practical and supported by case examples and resources.

(in particular, the information collected on appointment booking systems) and its ability to “flag up the problem”.
the 18-week target, whereas this was not the case for follow-up data.

4.3.16 The Trust’s serious incident report stated: ‘Clinicians were not informed that their patients were not being booked as requested.’ Elsewhere in the report it was documented that ‘although numbers of patients (thousands) waiting outside of the timeframe were reported to clinicians... this was sporadic and did not include clinical priority or risk stratification’.

The Care Group Management Team Operations Manager explained that since at least 2013 the PSC sent consultants a report on the numbers on the capacity database but agreed it was sporadic. He confirmed that the report did not stratify patients according to their risk of vision loss or include how far outside the requested timeframe patients were booked. Given that the report listed thousands of patients, it was not possible for consultants to consider patients individually or to know who should be prioritised for appointments.

4.3.17 Consultant A informed the investigation that it started to become evident that patients were being booked long after requested timeframes when they attended clinics much later than expected and/or were contacting the ophthalmology secretaries. The consultant said that at this time the consultants began submitting clinical incident reports, which included the harm caused, or risk of harm. The Trust’s serious incident report comments on two incident reports from July and August 2017, following which a review of all
patients on the capacity database was initiated.

4.3.18 In November 2018 the Trust sent a letter to all patients with glaucoma apologising for delays in appointments and the anxiety caused. The letter informed patients that the HES was unable to meet the demand for its services and advised them of ongoing efforts to manage the situation. The Medical Director explained that he wanted to communicate with patients directly and be open with them about the capacity problems. He said the subsequent feedback from patients were helpful. GPs were also made aware of the problem. The Medical Director told the investigation that he had also written to NHS England/Improvement but had not received a response.

4.3.19 The investigation was made aware of a workaround that at least one consultant had developed to ensure patients at high risk of loss of vision (requiring follow-up within three months) were seen within the requested timeframe. The workaround was to give the routing slips from outpatient clinics directly to the Operations Co-ordinator to book, rather passing them to the PSC for booking. This workaround reflected both concern about patients being lost in the system or being booked beyond the requested timeframe, and also the trust and respect in the knowledge and skills of the Operations Co-ordinator, with whom the consultant had an established working relationship. Although this consultant said she thought there were more regular meetings now between the Care Group Management Team and the PSC, and
improvements in management of follow-ups, she said she was “scared to test the system” as a result of the delays she had witnessed in patient pathways and harm caused as a result, the reference event being one such example.

4.3.20 The investigation was informed of the benefits of the staff who book appointments being based within the HES; they were in close contact with the ophthalmologists and this fostered the building of relationships. The Clinical Lead of the Care Group Management Team noted that when the booking was ‘in-house’, there was much greater communication and “they would knock at our door” to ask about appointments or raise issues. The Operations Manager said this resulted in a much more flexible system and facilitated learning about the specialty. He pointed out that this flexibility and acquisition of learning was much harder and slower in a central booking team that is physically remote and has a high turnover of booking staff. However, the Divisional Director of Operations gave an example of a neighbouring hospital with an in-house booking service which had exactly the same issues, so stated this was not a solution. In addition, he said that for high-volume specialties where there were set standards for follow-up, a centralised booking team was more efficient.

4.3.21 The 2009 National Patient Safety Agency (NPSA) Rapid Response Report [9] highlighted the need for Trusts to ‘review their systems and processes [and ensure they had] robust booking systems which respond to clinical priorities’. One of the six recommendations for ‘immediate action’ was to: ‘Develop a
system whereby patients can be flagged on the booking/appointment system to indicate the clinical priority given to the appointment and monitor activity to ensure compliance with NICE follow-up intervals.’ This was not in place in the HES where the reference event took place at the time of the event. In May 2018, based on guidance published by the Royal College of Ophthalmologists [13], NHS England published a document [12] describing three actions, two of which were directed at HES to minimise the risk of harm to patients most at risk of sight loss. The document provided practical details and case studies. Key elements of the actions included:

- Review existing patients to establish how many patients are awaiting follow-up, have a follow-up booked beyond the clinically indicated timescale, or have been ‘lost’ (note 38). This exercise will allow the scale of the backlog and the need (demand) to be identified.

- Clinical review of the patients awaiting follow-up, stratifying them according to their risk of harm and specifying a date for follow-up with the patient.

- Prioritising appointments based on patients’ risk of sight loss and intended date for follow-up.

- Ensuring the patient administration system can record diagnosis, risk, priority status and intended date for follow-up.

- Appointing a failsafe officer in ophthalmology departments to ensure these processes are implemented and to audit their implementation.
Changes made by the Trust in response to their investigation into delayed follow-ups for glaucoma patients included these actions.

Summary

4.3.22 There was awareness at all levels of the Trust, and externally by commissioners, of the growing lack of capacity for follow-up appointments, resulting in an inability to book follow-up appointments in requested timeframes. However, because the risk control in place (the capacity database) was not fit for purpose, there was a lack of appreciation of the scale of the problem and risk of harm to which patients were exposed.

4.3.23 The design of patient information systems hampered meaningful oversight of the safety issue. The national focus on the 18-week referral to treatment target, rather than follow-up within the requested timescale, had deflected attention from the follow-up problem. Changes made to electronic information systems enabled more meaningful oversight. That said, issues remain with the quality of the data on the capacity database, necessitating time-intensive validation exercises.

4.3.24 Review and risk stratification of existing glaucoma patients has meant appointments can be prioritised for those at greatest risk of vision loss.

4.3.25 Investigation of individual incidents of harm led to an understanding of the scale of the capacity issue and risk of harm. The Trust was open about this
and wrote to all glaucoma patients with an apology, acknowledgment of the problem and assurance that action was being taken.

4.3.26 A national focus on the issue of capacity in ophthalmology services has led to the publication of recommendations and case examples to share learning. Some of the recommendations mirror those made by the NPSA in 2009.

4.4 Actions resulting from the Trust's internal investigation

4.4.1 The Trust’s internal investigation resulted in several safety actions to reduce the risk of recurrence. The key actions were:

**Safety action 1:**
Development of new pathways for patients with glaucoma. Pathways to include the requirement for referrals to the HES to be validated by the existing community ophthalmology service, and identification of patients who can be transferred to community services for ongoing monitoring and management.

**Safety action 2:**
Expansion of the workforce through: a business case for a fourth consultant specialising in glaucoma; recruitment of a clinical fellow; recruitment of a nurse practitioner; recruitment of optometrists; and recruitment of a failsafe manager (to track patients at high-risk of loss of vision and support the booking team).

**Safety action 3:**
Review of physical space and utilisation of peripheral clinic and theatre capacity.

**Safety action 4:**
Increase the use of virtual clinical reviews.
26 The PSC Team Leader had just started in post (and was new to the Trust) at the time the investigation visited the hospital, so the investigation also met the Deputy Team Leader, who had three years’ experience of working in the PSC.

27 The NHS Constitution states that patients in England should wait no longer than 18 weeks from GP referral to treatment.

28 Calls made on 5 March 2019 were reviewed.

29 A clinical fellow is a medical doctor undertaking postgraduate training in a specialty outside a recognised medical royal college training programme.

30 The Trust’s clinical services are divided into four divisions. Ophthalmology is in Division B. Other care services included in Division B are Medical Outpatients; Pathology; the Emergency Department; Air Ambulance; and the Medical Assessment Unit.

31 The term retinopathy covers various disorders of the retina (the thin layer of tissue at the back of the eye) which can affect vision. Retinopathy is commonly caused by diabetes.

32 Age-related macular degeneration is an eye disease that can progressively destroy an area of the eye known as the macula, which is the central portion of the retina, impairing central vision. It typically affects people over the age of 60.

33 Clinical Services are overseen by a Care Group Management Team. The team has a clinical lead, operations manager and care group manager. The investigation was informed that the role of the team was to direct the strategic development of ophthalmology services, ensure appropriate governance and monitor performance. The team reports to, and is monitored by, the Divisional Management Team.

34 In England and Northern Ireland, people over 60 years old and those diagnosed with glaucoma, or over 40 years old and considered to be at risk of glaucoma (according to an ophthalmologist) are entitled to free NHS eye tests.
35 When the investigation visited the Trust in February 2019 a new Care Group Manager was in post.

36 Of note, this comment reflects work by Weick and Sutcliffe [42] about the characteristics of high-reliability organisations. One of these is having a strong response to a weak signal. The authors state that it is natural to have a weak response to a seemingly small occurrence, but highly reliable organisations recognise the dangers that small events can pose if not addressed in a convincing manner. High-reliability organisations distinguish themselves from others because of their mindfulness, which enables them to see the significance of weak signals and to give strong interventions in response.

37 NHS England/Improvement merged in April 2019. Prior to this they were separate entities. They are, therefore, referred to both singularly and jointly in this report depending on the date of the document being cited.

38 That is, the patient has not been discharged but no review has been booked and no clinically indicated date for review has been identified.
Findings and analysis from the wider investigation

This section describes the investigation’s findings in relation to the identified safety issues affecting the lack of timely monitoring for patients with glaucoma within secondary care (note 39). The investigation recognises that there are challenges with follow-up appointment capacity for other chronic eye conditions, but they are outside the scope of this report. Some of the findings will be relevant to conditions in other specialties that require long-term follow-up and where challenges exist regarding capacity.

5.1 Increasing capacity to meet demand

5.1.1 Ophthalmology is the highest volume outpatient specialty in England, providing over 7.5 million outpatient appointments a year (note 40). The lack of capacity to meet demand for hospital eye services (HESs), particularly for follow-up appointments, is well recognised. The Royal College of Ophthalmologists (RCOphth) 2018 Workforce Census found that 85% of HESs were undertaking waiting list initiatives in an attempt to manage demand [14].

5.1.2 On average a person diagnosed with glaucoma will have an initial visit and 40 follow-up visits [21]. In 2009 the National Patient Safety Agency (NPSA) drew attention to sight loss caused by delayed follow-up appointments [9] and reports published in recent years have further highlighted the problem [10, 12]. In 2017 the RCOphth stated that 57% (25 out of 44) of the ophthalmology consultants they interviewed reported a backlog causing delays to follow-up appointments [5]. The British Ophthalmological Surveillance Unit
found that up to 22 people per month were experiencing permanent and severe vision loss due to health service-initiated appointment delays [11].

5.1.3 The investigation spoke to patients attending glaucoma clinics at HESs to hear their experiences. Interviews were arranged through the International Glaucoma Association and Royal National Institute of Blind People (note 41). One person interviewed was newly diagnosed and had not yet reached the time for follow-up. Of the remainder, all had experienced delays in appointments. One patient had waited over a year. The investigation heard patients’ experiences of repeatedly chasing for appointments in an effort to be seen close to the date for review stated by their ophthalmologist. A theme from interviews was that the situation was “getting worse each year” with patients being told by the booking team that there were “no appointments” or that appointments “were running behind”, with one person being told “about a year behind”.

5.1.4 Views about what would have happened if they had not chased their appointments were summed up by one person who doubted they would have received one at all or “not for a very long time”. Two of the patients the investigation spoke with had involved the hospital’s Patient Advice and Liaison Service (note 42) for help with getting an appointment.

5.1.5 Those interviewed highlighted the need to have confidence to chase the hospital for an appointment. One patient said: “I feel very comfortable…I will push for an
appointment.” Another stated: “You have to take responsibility for making sure you're seen anywhere near the time you should be.” Several interviewees noted that for some people this may be more difficult due to timidity or not possible at all due to cognitive impairment, a language barrier or other reasons. This puts those patients at greater risk.

5.1.6 The 2017 RCOphth report described innovations and service redesigns implemented by different HESs to increase capacity [5]. National initiatives such as Getting It Right First Time (GIRFT) [22] and the Elective Care Transformation Programme [23] are also contributing to, and enabling, the reconfiguration of ophthalmology services to address demand.

5.1.7 Ensuring sufficient capacity to meet growing demand may be described as a preventive risk control. This control has been inadequate to date and as a result of the mismatch between capacity and demand, there has been a focus in recent years on mitigation of harm (recovery risk controls) as well as strengthening preventive risk controls. Current capacity can be maximised by:

- ensuring referrals to, and follow-ups by, HESs are necessary
- introducing new ways of working - in particular, pathway redesign and use of other members of the multidisciplinary team to take on tasks that were previously performed by ophthalmologists.
Referral to hospital eye services

5.1.8 Patients with suspected glaucoma can be referred to a HES directly from their GP or from primary care-based optical practices. Optometrists can identify approximately 95% of cases of possible glaucoma [24]. Cases of glaucoma are identified opportunistically when tests are carried out as part of NHS sight tests. When the patient is seen in the HES, further assessment and testing for glaucoma is performed. If a patient has glaucoma, they will require a follow-up appointment; if the suspected diagnosis of glaucoma is not confirmed they are discharged. Therefore, a proxy marker for whether a referral is clinically required is whether the patient is discharged or not after their first appointment in the HES.

5.1.9 An analysis of 2,505 referrals for suspected glaucoma to one eye department over a 10-year period showed that 45.8% of patients were discharged at first visit, and 20.4% were confirmed as having glaucoma [25]. The RCOphth states that ‘these false positive referrals can be viewed as suboptimal use of the secondary care resource and the rate has conclusively been shown to be amenable to reduction by a variety of [glaucoma referral filtering schemes]’ [5].

5.1.10 Glaucoma referral filtering schemes comprise a hierarchy of different pathways used to reduce false positive glaucoma referrals. Most schemes involve the deployment of optometrists who have undergone further training and accreditation. The schemes range from repeating measurement of intraocular pressure, to taking other clinical measures, to a more comprehensive clinical evaluation.
A study in Bradford investigating optometric referrals found that, as the referring optometrists gained experience, false positive referrals decreased at a rate of 6.2% per year [26]. The authors found that those who conducted further investigations as part of an enhanced service were 2.7 times less likely to make false positive referrals. A scheme in Bexley in which the referring optometrist conducted repeat tests prior to referral found this resulted in 76% of patients with suspected glaucoma patients not being referred [27].

The 2016 commissioning guide for glaucoma recommended that commissioners ensure they commission services that allow people with suspected glaucoma to be assessed in the community before referral to a consultant ophthalmologist if glaucoma is still suspected [21]. The National Institute for Health and Care Excellence (NICE) guidance and quality standards also support this (note 43) [8]. Interviews with glaucoma leads for the RCOphth report, The Way Forward, found that glaucoma referral filtering schemes were widespread, with 66% (31 out of 47) of those interviewed indicating that referral filtering was in operation in their locality [5].

A study of the effectiveness of referral filtering schemes in the UK found that they were effective in reducing the false positive rate [28]. In its 2017 report [5], the RCOphth states that a first visit discharge rate (false positives) of around 40% should not be considered high if referral filtering is not in place. It describes different schemes and examples of specific successes, such as one scheme where the first HES visit discharge rate was reported as 8% and
another where the scheme resulted in 1,400 HES glaucoma clinic slots being freed up each year [29].

5.1.14 The Local Optical Committee Support Unit informed the investigation that figures from its central data repository showed that over 10,000 patients were seen in repeat measurement schemes in 2017/18. Two thirds of these did not require a hospital appointment thus freeing up capacity in HESs to deal with the most complex cases (note 44). In addition, provision of such schemes can save patients travelling to the HES, which may be a significant distance from their home.

5.1.15 The investigation spoke with a consultant ophthalmologist and consultant optometrist who were co-authors of the evaluation of the Manchester glaucoma enhanced referral scheme. Established in 1999, this was the first such scheme to be set up. Early evaluation of the scheme observed a reduction in false positives from approximately 40% to 10%. A subsequent evaluation of 1,404 patients also found the scheme to have both a low false positive rate (15.5%) and low false negative rate (note 45) (0.8%) [30]. The consultants thought the scheme could be replicated and said that following the published evaluation, they had been contacted by those setting up schemes in other areas who planned to adopt or adapt their model to suit local context.

5.1.16 There is no standardised service delivery for glaucoma referral filtering schemes; they are commissioned and designed locally. Furthermore, the two consultants in Manchester pointed out
that commissioners need to agree to fund such schemes, and that competing priorities in a financially stretched environment may inhibit development of such schemes (see 5.2.47).

5.1.17 The two consultants highlighted that while schemes may allow efficient use of HESs, this is conditional on sound governance and working arrangements between HESs and community and non-medical practitioners, suggesting the benefits of a consistent approach based on an evaluated scheme.

5.1.18 Glaucoma referral filtering schemes can be located in the community or within HESs. If located within an HES they may negatively impact on limited space, but, as the RCOphth states: ‘It may be a large leap to instigate a [glaucoma referral filtering scheme] from scratch in the community, but commencing in a HES department (in high population density areas)...can make initial training, equipping and clinical governance issues much easier to navigate. The scheme can then be moved out into the community when established.’ [5]

5.1.19 Despite evidence of schemes successfully reducing glaucoma referrals to HESs, the RCOphth found differing perceptions of the efficacy of schemes and differing levels of collaboration and communication. In addition, a scheme’s impact in terms of eliminating false positive referrals to HESs may vary over time; the RCOphth highlights the importance of any newly commissioned glaucoma referral filtering scheme having ‘a robust continuing evaluation process [and quality assurance]...to ensure value’ [5].
5.1.20 There is the potential for automated referral filtering in the future as imaging technology advances (identifying patients deemed at low risk of glaucoma based on the results of a range of eye tests). A study published in 2016 looked at one automated approach and found it to be cost effective but it resulted in one in seven cases of glaucoma being inappropriately discharged (that is, a false negative rate of 14.3%), so the technology was not sufficiently advanced [31]. However, use of technology makes it possible for referral filtering to be more machine driven while still involving some human input into decision making.

5.1.21 Two potential benefits of glaucoma referral filtering schemes are that seeing a patient in the community can save HES clinic time and may be less expensive than seeing a patient in an HES. However, the RCOphth states that the growth of virtual clinics (see 5.1.32 to 5.1.36), particularly for new patients, means ‘neither of the conditions that made setting up [glaucoma referral filtering schemes] desirable are as pressing as they once were’ [5].

5.1.22 When discussing referrals from community eye services to HES, one clinical lead was of the opinion that there was the potential for a screening programme for glaucoma. He pointed out that the range of tests and examinations carried out by community optometrists has expanded over the years to now include testing of intraocular pressure (IOP), visual field testing and sometimes photography and imaging. In an article he stated that these eye checks ‘have never been subject to the scrutiny of the UK National Screening Committee. But...represent a form of screening that is limited to people who access NHS
sight tests’ [32]. As such, demand, and, in his view, pressures on capacity, have been fuelled by, in effect, ‘unregulated screening’ [32] using tests that have “never been subject to validation”.

5.1.23 Commenting on glaucoma referral filtering schemes, the clinical lead described them in a British Medical Journal article as “paying opticians more to triage the unnecessary referrals they have initiated” [32]. Responses to the article highlighted the costs (financial and staffing) needed to undertake more sensitive testing and the need for the fee for NHS eye checks to be raised if optometrists were to routinely undertake these tests.

5.1.24 A review in 2007 considered screening for open angle glaucoma. Different screening models and their cost effectiveness were assessed. The review concluded that open angle glaucoma did not meet the UK National Screening Committee criteria for test or screening. It concluded that population screening for the condition was not cost-effective ‘but targeted screening of high-risk groups may be’ [33]. In 2018 the committee commissioned a review of the evidence (note 46). The outcome (note 47) was that a population screening programme still could not be recommended. The committee gave the following reasons in support of this recommendation:

• ‘there are no tests which can accurately predict who is going to develop the disease

• many people diagnosed with early glaucoma will never suffer visual impairment in their lifetime
there isn’t any good-quality evidence that demonstrates treatment to be better than no treatment. Additionally, the treatments can cause harm.

- the effectiveness of a screening programme has not been studied; therefore there is no evidence to suggest that a programme would reduce the burden of the disease to the UK population’ [34].

5.1.25 The joint clinical lead for GIRFT (and ex-president of the RCOphth) concurred that there was no evidence to support a screening programme for glaucoma. She pointed out that existing ophthalmic screening programmes have clear target groups, for example diabetic retinopathy screening for patients diagnosed with diabetes. It would be very difficult to identify the target group for glaucoma, hence patients are identified opportunistically based on risk factors established during eye checks.

5.1.26 NICE guidance updated in 2017 included the tests that should be used prior to referral, but the investigation was told that adherence to the guidance is poor. Several clinical leads stated that unless the requirements in the guidance were mandated through the NHS General Ophthalmic Services (GOS) contract and additional funding provided, adherence was unlikely to improve.

5.1.27 The investigation contacted a clinical lead for glaucoma in Northern Ireland where, although not included in the GOS contract, payment had been agreed for community optometrists to use standardised, more
specific tests prior to referral to an HES - in effect, referral filtering. The lead reported that this had significantly reduced the number of false positive referrals. In Scotland, additional tests to be undertaken before referral are included in the main Scottish GOS contract and in Wales they are included in the Welsh Eye Health Examination [21].

5.1.28 The joint clinical lead for GIRFT was not in favour of changing the GOS contract. In her opinion the more specialised testing (such as field of vision tests) should only be used when clinically indicated and linked to skills, knowledge and accreditation, as with commissioned referral filtering schemes. Changing the GOS would imply that all optometrists, regardless of training or willingness, will undertake such testing. Thus, referral filtering schemes give the benefits of an amended GOS - consultant ophthalmologists only seeing those at high risk of having glaucoma - without the potential disadvantages of a change in the GOS contract.

**Summary**

5.1.29 There is inadequate capacity to meet the demand for glaucoma services. Current capacity can be maximised by ensuring referrals to, and follow-ups by, HESs are necessary, and introducing new ways of working.

5.1.30 The vast majority of referrals to HESs are made by community optometrists. A significant proportion are false positives. To reduce the number of such referrals many localities have commissioned some form of glaucoma referral filtering.
5.1.31 The UK National Screening Committee does not recommend population screening for glaucoma.

**New ways of working – virtual clinics**

5.1.32 Virtual clinics involve tests such as visual fields, visual acuity, intraocular pressure and other assessments (such as retinal photographs and scans) being performed by non-medical healthcare practitioners or technicians. Review of the data is undertaken remotely by a consultant or specially trained non-consultant or non-medical healthcare professional, and patients are informed of the outcome. The Clinical Advisor for GIRFT said too often trusts failed to appreciate the resourcing requirements needed for virtual clinics to work optimally. For example, funding for consultant review may be agreed but not for the additional testing machines and technical staff, or vice versa. Clinical leads and subject matter advisors agreed that if properly resourced and set up, virtual clinics are very effective and significantly more patients can be reviewed than is possible in a face-to-face outpatient clinic, with several estimating up to three times more.

5.1.33 The RCOphth spoke with glaucoma leads to inform its report, The Way Forward. Of those interviewed, 46% (24 out of 52) said they had established virtual clinics to boost capacity [5]. Virtual clinics were more common in services where there was a problem with appointment backlogs (65% of glaucoma clinics with backlogs had set up virtual clinics to deal with the issue). Although IT inefficiencies were identified, the RCOphth concluded that ‘the functionality of IT for reviewing
longitudinal data with computerised assessment of progression or data from remote centres make computer based image and data review the clear option for the future’ [5]. The Way Forward report included examples of established virtual clinics which ran on IT systems and others which ran on paper-based notes. The report highlighted the risks of missing notes from the latter and the hidden costs of a paper-based system in terms of administrative staff retrieving, filing and printing documents.

5.1.34 Virtual clinics may be used to assess new referrals, or to follow up patients whose condition is stable (note 48), or those at low or medium risk of disease progression. The RCOphth states that one disadvantage of any service set up to care for patients at low risk is that patients who ought to be discharged may be retained. The RCOphth highlights that: ‘This emphasises the need for clear protocols that reflect good evidence and good supervision by consultants.’ [5]

5.1.35 Promoting different ways of working, in particular delivery of care outside the hospital setting which helps to reduce the number of times patients have to attend traditional appointments, is encouraged by the NHS Long Term Plan [35]. Provision of ‘virtual’, digitally enabled, outpatient appointments is an example of this. By transforming the outpatient model, the plan sets the expectation that up to a third of face-to-face, hospital-based outpatient appointments will be avoided over the next five years. The growth of virtual review for patients with glaucoma is one example of outpatient transformation.
The value of virtual clinics was a theme from interviews with clinical leads. However, the investigation was told that the lack of a nationally agreed tariff meant a lot of time was spent on “bureaucracy and billing”. In addition, the investigation was told that because proposed tariffs were lower than for traditional face-to-face follow-up, they did not incentivise this more efficient way of working (see 5.2.35 to 5.2.53).

New ways of working – selective laser trabeculoplasty as the principal method of treatment

A three-year study published in The Lancet [36] concluded that selective laser trabeculoplasty (SLT) should replace eye drops as the first-line treatment for glaucoma. It is possible that by reliably stabilising the condition after one treatment, the number of visits may be reduced – for example, visits related to non-compliance with eye-drops and/or treatment adjustment. However, clinical leads advised that SLT was only appropriate for some patients, did not always work, needed repeating in time, and regular follow-up was still required. They concluded that SLT may not make a significant difference to follow-up capacity. The Chair of Professional Standards for the RCOphth said that it may take several years before it was possible to make a judgement regarding the treatment’s impact on follow-up appointments.

New ways of working – different models of care and use of the multidisciplinary team

Shared care arrangements for care of patients with glaucoma are widespread.
They involve appropriately trained non-medical healthcare professionals working either in community settings (usually optometrists) or within HESs (optometrists, nurses and orthoptists), seeing patients whose glaucoma has been assessed as low risk. There are published examples of these types of arrangements dating back to the 1990s [37]. The RCOphth described different models, with the level of training determining the level of care provided, and different models of referral and oversight. Evidence shows that ‘appropriately trained community optometrists’ clinical examination of key parameters and resultant decision making can correlate well with glaucoma consultants’ [5].

5.1.39 The RCOphth report [5] found that 88% of clinics they contacted (45 out of 51) had incorporated non-ophthalmologists into their glaucoma services.

5.1.40 Table 2 illustrates the different roles non-ophthalmologists undertake in glaucoma services. The RCOphth states that ‘the key to organising a glaucoma service for a multi-disciplinary team depends on stratification of patients into low, medium and higher risk categories’ [5]. These categories are defined by them (and accredited by NICE) along with the training and qualifications required. The RCOphth suggests low- and medium-risk cases can be managed via a virtual service (model 1 in Table 2) or by healthcare practitioners (model 2 in Table 2) with consultant input provided as required. Medium-risk cases can be managed independently by healthcare practitioners who have a glaucoma qualification.
High-risk, complex cases are seen by ophthalmologists, commonly with a specialist interest in glaucoma.

5.1.41 The RCOphth has summarised the training requirements for non-medical eye healthcare professionals to meet the various levels of case complexity and be compliant with NICE guidance [17]. A competency framework exists for non-medical ophthalmic professionals working in secondary care [23] and this was developed into a curriculum in 2019 [38].

5.1.42 The College of Optometrists has developed three levels of higher qualification in glaucoma: Certificate, Higher Certificate and Diploma. The latter two give optometrists the opportunity to practise independently, looking after a clearly defined group of patients based on risk. One consultant ophthalmologist told the investigation of a model being developed in his area which involves patients at low risk being discharged to optometrists who hold the Higher Certificate or Diploma in glaucoma. He said this model not only relieves pressure on HES but also, unusually, creates an expansion of decision-making capacity. He pointed out that most other alternative ways of working involve multidisciplinary team members practising in a managed way, with a direct line of responsibility to a named consultant who remains the decision maker with ultimate responsibility.

5.1.43 The RCOphth’s report, The Way Forward, described different clinic models, such as treatment response clinics staffed by healthcare practitioners and face-to-face healthcare practitioner clinics based on clinical risk. Ophthalmologist input was reserved for the ‘sizeable minority’ of
Table 2 Multidisciplinary team involvement in glaucoma services [5]

<table>
<thead>
<tr>
<th>Data acquisition only - data then reviewed by ophthalmologist</th>
<th>Stable treated glaucoma/OHT monitored - concerns flagged up</th>
<th>Full management</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Nurse/Ophthalmic technicians/practitioners:</td>
<td>2 Optometrists/nurse practitioners/orthoptists</td>
<td>3 Optometrists/nurse practitioner/nurse consultant with glaucoma qualification +/- IP</td>
</tr>
<tr>
<td>- VA, Visual Field</td>
<td>- Running clinics alongside consultant</td>
<td>- Running independant clinics or alongside consultant</td>
</tr>
<tr>
<td>- IOP (GAT)</td>
<td>- Treatment variation according to protocol</td>
<td></td>
</tr>
<tr>
<td>- Pachymetry</td>
<td>- Seeking help appropriately for review/prescribing</td>
<td></td>
</tr>
<tr>
<td>- Disc (HRT/OCT/photo)</td>
<td></td>
<td></td>
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<tr>
<td>- +/- gonioscopy</td>
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complex or unstable cases or younger patients. Based on evidence gathered, the report suggested that ‘it may be possible to double capacity with appropriately trained [healthcare practitioners] working alongside ophthalmologists’. However, the report emphasised the importance of leadership that an ophthalmologist provides, stating: ‘Ophthalmologist leadership and ownership of services is the single most important factor that determines the success of any service design.’ Hence there was ‘a limit to the reduction in proportionate consultant numbers that can be sustained’ [5].

5.1.44 Glaucoma clinical leads shared their experiences of different ways of working. The value of utilising the multidisciplinary team to increase capacity was reflected in interviews but space was a limiting factor for some (see 5.2.58).

Another theme was the importance of close collaboration and consultant ophthalmologist oversight and support, echoing the similar conclusion in The Way Forward [5]. The investigation spoke with clinical leads who had moved services in house from community settings (but still using the multidisciplinary team) to facilitate this closer working and oversight.

5.1.45 The demand for glaucoma services has been predicted based on the ageing population (see 1.1.5). The different ways of working introduced to manage the demand have resulted in growing evidence of which initiatives have been most successful and the space, equipment and staff required to deliver them.

5.1.46 The GIRFT report found significant variation in service delivery between
HESs [39]. The President of the RCOphth concluded that it was now time to “stand back” and review the delivery of glaucoma care across the whole pathway, from referral to HES to discharge, and model what would be the most cost-effective, efficient and safe way to deliver care. He pointed out that glaucoma was very amenable to such modelling as the demand should be predictable based on local demographics, and the care and follow-up required is well understood and has already been set out in protocols. He believed such modelling would then be applicable to other chronic eye conditions and, potentially, conditions in other specialties. The President believed that this would save costs (by eliminating inefficiencies) as well as ensuring consistent, safe care for patients.

5.1.47 The Clinical Council for Eye Health Commissioning has modelled pathways of care for the main adult chronic or high-volume eye conditions, including glaucoma. In 2018 it published the System and Assurance Framework for Eye-Health (SAFE) [40]. The framework provides a high-level model – ‘the overall architecture’ – to assist commissioners and provider organisations in strategic service planning. The specific framework for glaucoma stated the different services to be commissioned, based on risk of sight loss, to deliver glaucoma care. The framework included the relevant guidelines, tools and metrics for monitoring services [41].

5.1.48 The Chair of Professional Standards for the RCOphth was strongly in support of the further modelling proposed by the President and the additional value it would
bring. She stated that it could move things forward by making “more clear, explicit and detailed the ‘recipe’ for staffing models and pathways which can then be taken and implemented (with editing for local purposes and population)”. She said that from her visits to services across the UK “very few regions have cracked delivering services”. The Chair pointed out that “there are systemic barriers to these around IT, staffing and training and payments which need unlocking”.

5.1.49 Looking forward, the Chair of Professional Standards anticipated that new technologies, treatments, and ways of working could be fed into the methodology developed to recalculate service requirements. Thus, the modelling would be “the beginning of an ongoing forward planning system”.

5.1.50 The value of modelling the glaucoma pathway was endorsed by other ophthalmologists interviewed by the investigation. For example, it was pointed out that this could answer the question of the most cost-effective and efficient way to manage referrals to HESs.

5.1.51 The value of modelling was reflected in comments by the Executive Director of Education and Quality (and National Medical Director) for Health Education England. She pointed out the need to first agree the most cost-effective and safe pathways to deliver care, and then to assess any shortfall in workforce to deliver it.

5.1.52 Both the President of the RCOphth and its Chair of Professional Standards were keen for the modelling to be co-developed with NHS England/Improvement to maintain national leadership and close collaborative
working between the two organisations. The Director of the National Elective Care Transformation Programme for NHS England/Improvement supported this.

5.1.53 The joint clinical lead for GIRFT told the investigation of the significant difference the involvement of NHS England/Improvement had made to progressing changes needed to address capacity. Clinical leads and service managers echoed this view.

**Summary**

5.1.54 HESs have developed new ways of working and models of care to increase capacity.

5.1.55 Virtual clinics appear to be particularly valuable and can be used for both filtering new referrals and for follow-up of patients at low or medium risk of disease progression. Virtual clinics align with the aims of the NHS Long Term Plan to reduce the number of times patients have to attend traditional outpatient appointments.

5.1.56 One key area of the focus to increase capacity is pathway redesign to enable other adequately trained members of the multidisciplinary team to take on tasks previously performed by ophthalmologists.

5.1.57 There is sufficient evidence regarding alternative ways of working to develop models of optimal delivery of glaucoma care.
HSIB makes the following safety recommendation

Safety recommendation 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.

5.2 External systemic influences on demand and capacity

5.2.1 Evidence gathered by the investigation indicated that a number of external factors have influenced demand and capacity. Furthermore, there has been a lack of appreciation by some stakeholders of the scale of risk posed to patients.

The response to the growing mismatch between capacity and demand has been weak. A strong response to a weak signal has been identified as a characteristic of highly reliable, safe organisations [42], but on this issue there has been a weak response to an increasingly strong signal.

National referral to treatment target prioritises newly referred patients over patients requiring follow-up

5.2.2 The investigation interviewed a number of clinical leads and service managers responsible for glaucoma services, along with national leads for ophthalmology. A compelling theme from interviews was the belief that the national 18-week referral to treatment (RTT) access standard (note 49) or target had resulted in newly referred patients being prioritised over follow-up patients. Opinions were summed
up in comments by two consultant clinical leads; one said that “medicine has become target based not thinking based” and the other said the target had “distorted clinical priorities”.

5.2.3 Evidence from interviews indicated that hospital managers were focusing on ensuring first hospital appointments were within timescale but there was no equivalent focus on follow-up appointments being within requested timescales. As one consultant lead said: “If it’s not a target, no-one cares much... it’s under the radar.” The RCOphth stated: ‘The lack of capacity is exacerbated by the 18 week RTT, which can act as a perverse incentive to prioritise new over follow up patients.’ [43]

5.2.4 Within ophthalmology, the patients most at risk of avoidable sight loss are follow-up patients. Compared with new referrals, follow-up patients are eight to nine times more likely to have a sight-threatening condition that needs long-term monitoring and treatment [13].

5.2.5 A review of the NHS access standards began in June 2018. An interim report published in March 2019 acknowledged that while performance targets had incentivised improvements in care: ‘It is well documented that the current performance measures can have unintended consequences, pushing hard-pressed staff to focus on targets rather than patient need – “hitting the target but missing the point.”’ [44]

5.2.6 In its 2018 report, the All-Party Parliamentary Group on Eye Health and Visual Impairment recommended that a national target be established regarding
follow-up appointments being within clinically appropriate times [10]. Its aim was to redress the balance so that patients requiring follow-up are given equal priority to those needing a first appointment.

5.2.7 All those interviewed agreed that targets focus attention and are an enabler of change. However, concern was expressed about the bureaucracy needed to demonstrate compliance and the way lack of compliance can be used as “a stick to beat you with”.

5.2.8 The joint clinical lead for the GIRFT ophthalmology programme said that the possibility of a national target for timeliness of follow-up appointments had previously been explored with NHS England. The investigation met with the Director of Clinical Policy, Quality and Operations for NHS England/Improvement to discuss the possibility of a national follow-up performance or quality measure. She said that although prioritisation of follow-up appointments may be appropriate for ophthalmology patients with conditions such as glaucoma, such a target would not be appropriate across all specialties; for some it may be desirable to reduce follow-ups.

5.2.9 The Director of Clinical Policy, Quality and Operations for NHS England/Improvement referred to the national programme of work on transforming outpatient services, which takes account of differences between specialties. She believed that this programme could seek to optimise follow-up activity for ophthalmology (specifically glaucoma and other chronic
eye conditions), which might include the monitoring of quality measures.

5.2.10 While monitoring a quality measure regarding timeliness of follow-up appointments may be helpful, it would not be as powerful as a mandated target along the lines of the 18-week RTT. This gives patients the right to be treated within 18 weeks and places an onus on HESs and commissioners to offer a suitable alternative if they cannot comply. In addition, it places a duty on providers to review and investigate on a monthly basis the pathways of patients who have waited longer than 18 weeks in order to understand the causes of delay and inform improvements; and it requires reporting of this information to trust boards and commissioner(s) [20]. The RTT is included in the NHS Standard Contract which is mandated for use by commissioners for all contracts for healthcare services other than primary care. This document sets out service specifications and requirements against which providers must report evidence of compliance and provide assurance of remedial action where needed [45].

5.2.11 The possibility of introducing a standard measure (or metric) for follow-up appointments performance was discussed with the Director of the National Elective Care Transformation Programme. She agreed that mandated performance measures can be a powerful enabler of change. The importance of timely follow-up has been central to her team’s work with ophthalmology (see 5.3). However, she said that agreement would need to be reached about where, organisationally,
the metric should sit. The Senior Policy and Implementation Lead for the National Elective Care Transformation Programme said that it was unclear to what extent ophthalmology would sit within the wider outpatient transformation programme in the future.

5.2.12 Given the uncertainty, greater assurance regarding monitoring and scrutiny by commissioners would be achieved by inclusion of a follow-up appointments performance standard in the NHS Standard Contract. In addition to monitoring the overall measure of performance, there should also be a contractual requirement – as in the 18-week RTT – to identify and take action on individual patient pathways where the performance standard has not been met.

5.2.13 Inclusion of a follow-up appointments performance standard in the NHS Standard Contract was discussed with the Senior Lead for the contract. He explained that, because the contract is used to commission a wide range of services, the requirements in it are usually expressed at quite a generic level. He said it would be inappropriate to include, within the nationally mandated provisions of the contract, very detailed ongoing requirements relating to a specific patient service such as glaucoma. However, he informed the investigation that under the contract, commissioners and providers are able to agree and implement a time-limited service development and improvement plan (SDIP), as a way of addressing and demonstrating a very specific issue. This is particularly relevant when a performance standard
is new or is likely to take time to achieve, and in these situations NHS England/Improvement may require commissioners to agree an SDIP to cover a particular topic. This may be a helpful lever to embed practice set out in existing guidance and to ensure that risk controls are in place to mitigate harm from delayed follow-up (see section 5.3).

5.2.14 Several clinical leads emphasised the differences in risk of vision loss in different subgroups within the cohort of patients with glaucoma. Vision UK’s Ophthalmic Public Health Committee (note 50) has developed a Portfolio of Indicators for Eye Health and Care (PIEHC). In relation to the monitoring of patients, the performance standard (note 51) set is that 95% of hospital appointments occur within no more than an additional 25% of the recommended follow-up period, including rescheduling of hospital-initiated cancellations and non-attendance by patients [46]. This measure is referenced by NHS England in its interventions for ophthalmology document [12]. The Clinical Advisor for GIRFT expressed concern that it might be possible for this standard to be met without some patients who are most at risk being seen. She was keen to ensure that this blanket performance measure did not disadvantage patients at high risk of sight loss. Although she agreed with the 25% adherence metric being the primary measure, she emphasised the importance of risk stratification (see 5.3) to identify those patients where a delay in follow-up was most likely to result in vision loss. She estimated this group of patients to be up to 15% of the follow-up cohort based on published research [47].
5.2.15 The joint clinical lead for the GIRFT ophthalmology review (and ex-president of RCOphth) explained the advantages of a performance measure which encompassed all patients with glaucoma. Firstly, a target that focused only on patients at high risk of vision loss may mean other groups of patients are ignored and/or their follow-up appointments become further delayed. Secondly, applying the target to the whole cohort of glaucoma patients may stimulate behaviour changes that will positively influence capacity and demand, for example, the discharging of patients who do not need follow-up. The Clinical Advisor for GIRFT acknowledged the results of an audit of follow-up which showed approximately 30% of requested follow-up appointments were overly early, contributing to backlogs (see 5.2.65 to 5.2.71). Thirdly, if 95% compliance was achieved, most patients at high risk of vision loss would be within that cohort. Given that trusts are expected to have stratified their patients according to risk, it would be reasonable to expect that they prioritised appointments for those patients at highest risk of vision loss (see 5.3).

5.2.16 The importance of the 18-week target is reinforced by the nationally mandated requirement for trusts to report on compliance. Hospital IT systems have been configured accordingly. There is not a mandated requirement to report on follow-up appointments being within requested timescales. Since the reference event, the Trust where it occurred has amended its patient administration system to enable it to monitor and report on delayed follow-up appointments.
5.2.17 The importance of IT systems being designed to make easily visible the magnitude of the mismatch between capacity and demand, and the scale of delayed follow-up appointments, has been recognised. Joint guidance for HESs was issued in 2018 by the RCOphth, NHS England and NHS Digital to support providers of eye services to configure their patient administration systems to enable them to collect the necessary data [48]. The guidance stated that the recommended follow-up date should be entered in a pre-existing but seldom-used data field on patient administration systems which maps to the national outpatient Data Set. This allows the data to be extracted and published nationally by NHS Digital. The data field is named ‘Earliest Clinically Appropriate Date’. As the Lead Information Analyst for NHS Digital stated, the data field was not intended to be used by ophthalmology to record the date of the planned follow-up appointment. Hence the name is not helpful and does not intuitively suggest its use for entry of the recommended follow-up date. While trusts have been told to use this field to collect the recommended follow-up date, it is not a mandated data item so, while it is good practice, collection of this data is optional (see 5.3.11). Interviews with clinical leads identified that configuration of patient administration systems had been achieved in some but not all trusts.

5.2.18 The investigation met with representatives from NHS Digital to discuss their ability to report on delayed follow-up, and, specifically, compliance with the performance measure in the PIEHC. They stated that this would
be possible if the identified field on the patient administration system is completed by trusts, allowing compliance to be calculated. This would also allow national comparisons of performance to be made. In May 2019 NHS Digital published for the first time whether the data field for the recommended follow-up date (the Earliest Clinically Appropriate Date field) was completed by provider, by month, between April 2018 and March 2019 (note 52). At the time of the Healthcare Safety Investigation Branch (HSIB) investigation the data collected was not being used by NHS Digital to calculate compliance with the follow-up performance measure in the PIEHC.

5.2.19 The investigation was informed that analysis of the data to report on compliance would be new work for NHS Digital so would need to be commissioned. The Senior Policy and Implementation Lead for the National Elective Care Transformation Programme said that NHS England/Improvement could be the commissioners, as it had been working closely with NHS Digital to support transformation in ophthalmology.

5.2.20 NHS Digital had anticipated that most providers of NHS eye services would be completing the field identified to enter the recommended follow-up date. However, the principal information analyst said that in early 2019 very few providers were collecting the data. He estimated that of approximately 300 providers (note 53), about 10 were completing the data field that would allow the delay in follow-up appointments to be calculated. By
September 2019, 1% of HES submitting data had completed the relevant field (note 54).

5.2.21 The principal information analyst said that although providers were only being asked to complete one extra field, it seemed there had been significant barriers. These included the number of different patient administration systems in use and location of the relevant data field; over-writing of dates when appointments were cancelled or not attended and a new date had been requested; lack of IT and administration training and support; and, importantly, a lack of imperative or incentive to ensure data completion as it is not a mandated item. Inclusion of a follow-up performance measure in the NHS Standard Contract could focus attention on addressing these issues.

5.2.22 The Chair of Professional Standards for the RCOphth told the investigation that when the 120 or so trusts in England were canvassed regarding whether they routinely collected this data, only five reported that they did. The RCOphth stated that collection of such data ‘must become mandatory’ and it is one of the three steps it identified as necessary to reduce risk for eye patients [13]. Similarly, one of the recommendations to NHS England made by the All-Party Parliamentary Group on Eye Health and Visual Impairment was ‘to implement routine data collection...on waiting times for follow-up appointments, delays to follow-up outside clinically recommended timescales, patients lost to follow-up and consequences’ [10].

5.2.23 Interviews with clinical leads confirmed support for mandated, centrally reported
data on delayed follow-up appointments. Opinions were reflected in a comment by one clinical lead who said such national data would highlight and quantify the capacity issue and variation. She added that the data would provide “a powerful statistic...[and a way of] getting heard”. The Chair of Professional Standards for the RCOphth and Clinical Advisor for the GIRFT review of ophthalmology said that ideally the data should be published monthly, or as a minimum quarterly, so that progress can be closely monitored and timely support provided where indicated.

5.2.24 Several clinical leads spoke about the importance of the response to such data, and the support provided to trusts who were struggling with capacity. One clinical lead highlighted the importance of learning from each other and clinical leads being able to share with peers what has worked well and what has not. As part of its work to transform ophthalmology outpatient services, and to build on the High Impact Interventions (HII) (see 5.3.3), NHS England has been sharing resources and examples of changes in ways of working via a community of practice online hub (note 55).

5.2.25 Ophthalmology services in Wales face the same challenges with capacity and demand as services in England, with similar solutions being progressed. A report by the Public Accounts Committee on outpatient follow-up across Wales was published in 2019. Based on the evidence gathered, the committee stated it had ‘significant concerns that the focus on meeting RTT targets has led to a greater priority being given to first appointments
rather than follow ups, regardless of clinical need' [49]. The committee noted that risk of sight loss was nine times higher among follow-up patients (90% versus 10%).

5.2.26 In August 2018 the Welsh government launched a performance measure for eye care services, along with funding for improved IT connectivity between community and HESs, and funding for expanded or newly established services such as virtual clinics or community-based monitoring of patients at low risk of sight loss. The performance measure aimed to redress the priority given to first appointments and ensure prioritisation was based on clinical need and outcomes for patients, rather than the length of time a person had waited. As in England, risk stratification was seen as central to prioritisation and the eye care performance measure defined three risk categories to support this (note 56). The performance measure is that 95% of patients at the highest risk should be seen within no more than an additional 25% of their recommended timeframe for follow-up.

5.2.27 Mandated reporting and publication of compliance against the performance measure began in shadow form in September 2018 with full reporting from April 2019. At the time of HSIB’s investigation, performance reports had been published for April and May 2019. The figures showed that around 65% of patients assessed as at the highest risk were seen at their recommended time for follow-up or within an additional 25% of that timeframe [49]. Speaking to BBC Wales, the Health Minister commented on
the importance of measurement as a first step in addressing the problem, stating that “it will tell us an honest picture of what we’re doing and what we still need to do” (note 57). A report by the National Assembly for Wales Public Accounts Committee included a quote from the Welsh government, which stated that the performance measure may be extended to other specialties facing similar challenges to those in ophthalmology [49]. The Welsh Health Boards also monitor and report on other targets that the glaucoma service redesign is aiming to influence, such as the number of glaucoma referrals to HESs [50].

Summary

5.2.28 The national 18-week referral to treatment target prioritises newly referred patients over those requiring follow-up.

5.2.29 The All-Party Parliamentary Group on Eye Health and Visual Impairment recommended that a national target be established regarding follow-up appointments being within clinically appropriate timeframes.

5.2.30 Within ophthalmology, the patients most at risk of avoidable sight loss are follow-up patients.

5.2.31 The performance measure in the PIEHC is that 95% of hospital follow-up appointments occur within no more than an additional 25% of the recommended timeframe. This measure is referenced by NHS England in its recommended interventions for ophthalmology.

5.2.32 There are significant differences in levels of risk of vision loss within the large cohort
of patients with glaucoma, so patients should be risk stratified and follow-up appointments prioritised accordingly.

5.2.33 NHS Digital could publish monitoring reports on compliance with the follow-up performance measure in the PIEHC if the relevant data was submitted by trusts and NHS Digital was commissioned to publish it. Only a minority of trusts are completing the data field needed, which is currently not a mandated data item.

5.2.34 Inclusion of the PIEHC follow-up performance measure in the NHS Standard Contract, along with a requirement to review pathways of individual patients where the target has not been met, would help redress the priority given to new patients. In 2018 Wales introduced a mandated follow-up target for ophthalmology patients at the highest risk of sight loss.

HSIB makes the following safety recommendations

Safety recommendation 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 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.

**Tariffs**

5.2.35 NHS England’s Director of the National Elective Care Transformation Programme stated that money was an “important enabler” of change. In England the financial tariff (note 58) for a follow-up appointment is less than for a first appointment (note 59). This creates a financial incentive to prioritise first appointments over follow-ups. This blanket approach to pricing does not allow for differences relating to the specialty and the conditions and patient pathways involved.

5.2.36 A consultant ophthalmologist and chair of the RCOphth working group on pricing summed up the effect of the tariff, saying “money is a strong lever”.

5.2.37 In an outpatient clinic, consultant ophthalmologists traditionally saw a mix of complex and relatively straightforward patients. In The Way Forward, the RCOphth stated that the move towards the management of low-risk and stable cases by other members of the multidisciplinary team, or outside HESs, meant a progressive shift towards consultants managing only complex cases, thereby increasing the ‘true average cost of an outpatient attendance in a department’. The RCOphth concluded that this ‘suggests tariff alteration to reflect complexity will need to be negotiated’ [5].
5.2.38 Interviews with glaucoma clinical leads confirmed that the patients they see in follow-up clinics have increasingly become those with complex and time-consuming cases. This was summed up by one consultant who said seeing straightforward follow-up patients now “simply doesn’t exist…we used to see 18 patients in a follow-up clinic…now we see eight and are over-running”.

5.2.39 There was strong support for a review of the tariff to “change the emphasis and focus”, as one clinical lead said. Another clinical lead thought that the tariff should be considered on a local basis, with an increase being dependent on other ways of working having been established for the lower-risk patients. The Clinical Advisor for GIRFT was supportive of this more nuanced approach. She also pointed out that there were other commissioning options available to drive improvements in quality and innovation (note 60).

5.2.40 The influence of tariffs was commented on by the All-Party Parliamentary Group on Eye Health and Visual Impairment. They stated that the current tariff ‘introduced financial incentives for providers to undertake more first attendances at the expense of follow-ups seriously disadvantaging patients with glaucoma… This is an unacceptable distortion of clinical priorities which puts patients at risk of losing sight’. They recommended NHS England ‘urgently review the National Tariff’ [10].

5.2.41 The joint clinical lead for GIRFT told the investigation that ophthalmologists had invested considerable effort in trying
to get the new and follow-up tariff to be more equitable. Agreement had been reached in 2019 for the follow-up appointment tariff in England to be increased. However, it remains the case that the financial reward for review appointments for patients at most risk of sight loss is smaller than for first appointments.

5.2.42 The Pricing Regulation Lead for NHS England/Improvement told the investigation that the payment system for outpatients was under review. The focus of the work was on the impact of payment mechanisms on activity and growth in cost, and the implications of this for future changes to the payment system.

5.2.43 The Pricing Regulation Lead shared a preliminary report with the investigation in June 2019. The report identified a number of key findings and implications for future payment systems:

- There was no clear evidence that the increased payment for first appointments had reduced the number of follow-ups. The data suggested that other factors had a significantly greater impact on follow-up rates than changes to pricing.
- There is substantial variation in the costs of new and follow-up appointments depending on the specialty involved. This implies that new payment mechanisms should, perhaps, be tailored to specialty-level activity.
- There is substantial variation in patient pathways, from acute episodic care to long-term chronic care. The implication
is that tailored payment systems may be more appropriate for each.

5.2.44 It could be argued that pricing for first and follow-up appointments should be cost based rather than weighted. The fact that the preliminary report did not find weighting had reduced follow-up activity as anticipated, and the differences in costing between specialties and pathways, strengthens the argument for pricing appointments based on actual costs. This would also contribute to ensuring that follow-up and first appointments have equal priority.

5.2.45 The Pricing Regulation Lead for NHS England/Improvement told the investigation that there was a plan to develop payment models that better reflected the cost of treating a patient for a particular illness, and which took account of the complexity of their condition to ensure allocation of resource to need. The RCOphth’s Chair of Professional Standards stated that discussions regarding funding for patients with glaucoma had highlighted the need to review the whole patient pathway including primary care, which is currently funded separately.

5.2.46 The investigation was informed of a specific review of ophthalmology pricing being undertaken by NHS England/Improvement. The Pricing Regulation Lead for NHS England/Improvement shared the following preliminary findings:

- ophthalmology follow-ups are less profitable than the average outpatient follow-up (and, conversely, an ophthalmology first attendance is more
profitable than the average outpatient first attendance)

- bigger differences in costs between first appointments and follow-ups in ophthalmology compared to the average of all specialties

- local variation between models of service and data collection

- variable use of community optometrists

- multiple commissioners creating fragmented commissioning, and low level of commissioner skill

- additional costs associated with complex cases.

5.2.47 The investigation was told of other concerns about tariffs. The Chair of Professional Standards for the RCOphth said that there were “no nationally agreed, consistent tariffs” for the different ways of working that needed to be encouraged. She said this meant individual providers and commissioners were spending time negotiating this for community optometrists, virtual clinics, shared care schemes and so on. She concluded that this time and duplication of effort could be saved by having nationally agreed tariffs or other payment processes which could incentivise the new ways of working needed. In addition, she suggested that the aim to reduce traditional face-to-face, hospital-based outpatient appointments in the NHS Long Term Plan strengthens the argument for reviewing tariffs.
5.2.48 The Senior Policy and Implementation Lead for the National Elective Care Transformation Programme concurred with the need for tariffs to encourage or, at least, to not disincentivise, new ways of working. She noted that there seemed “a reluctance, or fear” by commissioners to use the flexibility available to them in relation to certain payments such as those relating to service redesign. She described work in progress with five HESs that were setting up virtual clinics which included consideration of tariffs. This is likely to give guidance on national pricing for setting up such clinics.

5.2.49 The investigation discussed the tariff for innovative ways of working with the Pricing Regulation Lead and the Pricing Development and Regulation Director at NHS England/Improvement. They pointed out that although it is possible to agree local variation as the prices set are non-mandatory (note 61), in reality commissioners often did not, or did not have the skills to, make use of this flexibility.

5.2.50 In a presentation to a stakeholder meeting in June 2019, the Pricing Regulation Lead said: “Trusts do not seem to be moving outpatient activity from face-to-face to non-face-to-face settings.” The lower, non-mandatory prices included in the current tariff for non-face-to-face outpatient attendances were noted and the fact that “providers may lack at least a financial incentive to shift activity in this direction”. The implication was that: “Incentives to shift activity to non-face-to-face-to-face settings need to be strengthened.” These factors
suggest that it may be helpful to have a nationally led and agreed pricing structure to encourage innovative ways of delivering services.

5.2.51 The Pricing Manager at NHS England/Improvement made the investigation aware of work on cost modelling for virtual clinics being undertaken at a large teaching hospital. This showed actual costs to be greater than the nominal (non-mandatory) price set for a non-face-to-face appointment, confirming anecdotal evidence regarding this. He pointed out that there is an argument for equalising prices for face-to-face and non-face-to-face appointments, given that both involve specialist input and time.

5.2.52 The Chair of Professional Standards for the RCOphth told the investigation that all four nations of the UK were sharing the same capacity constraints and finding the same solutions; she said that the “only real difference is the commissioning of the innovative service”. As an example, she said that in contrast to England, the devolved nations were taking a nationally led approach to establishing ways of working with community optometrists (one of the key solutions to the capacity issue), meaning it was not left “to every single CCG [clinical commissioning group] to decide whether to do it and what tariff to pay”. This point was echoed by the Association of Optometrists and Local Optical Committee Support Unit. They described primary eye care services for glaucoma filtering and monitoring as ‘commissioned on a patchwork basis around the country [due to] the fragmented nature of commissioning (note 62)’. 
5.2.53 The glaucoma clinical lead for Belfast told the investigation of the eight-year journey to transform delivery of glaucoma care which had enabled demand to be met (note 63). She said that following the National Patient Safety Agency Rapid Response Report in 2009 [9], the national Health Board and local commissioners had decided to focus on glaucoma. Financial investment was provided to enable new ways of working, including the building of a new bespoke eye centre in the community in Belfast for all non-surgical treatment, along with central oversight of improvement.

**Summary**

5.2.54 The financial tariff for a follow-up appointment is less than for a first appointment. This creates an incentive to prioritise first appointments over follow-ups.

5.2.55 Consultants have progressively shifted to seeing more complex patients in follow-up clinics. Thus, the true average cost of a follow-up appointment is not reflected in the tariff.

5.2.56 A review of tariffs suggested that increased payment for first appointments did not have a significant impact in reducing follow-ups; there were significant differences in costing between specialties and pathways.

5.2.57 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 outpatient appointments is to be realised.
**HSIB makes the following safety recommendation**

**Safety recommendation 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.

**Physical space**

5.2.58 The Belfast glaucoma lead pointed out the benefit of new premises to accommodate different ways of working. The additional physical space had allowed technicians to be employed to carry out visual field tests (and other tests required) on the same day as a patient’s ophthalmology appointment, removing the need for a separate visit. The lead said that “this massively improved efficiency...if I was to pick the one thing that made a huge difference it would be this”.

5.2.59 The need for space to facilitate different ways of working was highlighted by the consultant in the reference event and echoed in interviews with clinical leads. They emphasised that this space was needed for eye tests and the machines and technicians necessary to perform them, rather than for consulting rooms. The importance of space was summed up by one clinical lead who said: “Our biggest limiting rate [to changing ways of working] is lack of clinic space.” The President of the RCOphth agreed that lack of space was a major issue.

5.2.60 The GIRFT ophthalmology review considered physical space in HESs.
Providers were asked if lack of space was a limiting factor in new ways of working to meet demand, and whether the physical layout of premises led to inefficiencies in levels of activity. Of the 52 providers who answered these questions, 49 (96%) said lack of space was a limiting factor for the delivery of care. The GIRFT report stated that over the last decade the number of ophthalmology outpatient appointments has increased by 40% and ‘Most departments were built, and space allocated, for significantly lower numbers of patients and fewer staff, based on a traditional method of delivering care’ [39].

5.2.61 One of the recommendations in the GIRFT report was for providers and commissioners to assess where space may be a constraint on the overall capacity or ability to deliver care (including new ways of working). Where this is an issue, the GIRFT report recommended that options to increase space be considered, including the provision of alternative care settings. Allied to this, the report proposed joint work by GIRFT and NHS England/Improvement to examine options and gather case studies for increasing space, such as using community settings and virtual service delivery [39].

Summary

5.2.62 Lack of space can inhibit new ways of working and limit capacity.

5.2.63 The GIRFT ophthalmology report acknowledged the significance of space and made recommendations to help address this issue.
Workforce numbers and professional behaviours

5.2.64 A theme in the investigation’s interviews was the shortage of consultant ophthalmologists. While deploying other members of the multidisciplinary team has freed up consultant time, there is still a shortage. This leads to many clinics being led by locums or inexperienced ophthalmologists, or those who do not have specialist expertise in glaucoma. A workforce census carried out by the RCOphth in 2018 (note 64) identified that:

- locums were being used to fill 127 consultant posts
- 42 consultant posts were unfilled
- 67% of units were using locums
- the number of locums had increased by 52% since the last census in 2016
- an extra 230 consultant posts were estimated as required to meet the rising demand for ophthalmology services for the next two years
- this increase of 22% more consultants compares with an estimated 8% increase in posts required in 2016.

5.2.65 One clinical lead for glaucoma services told the investigation that one factor impacting on HES capacity was “self-inflicted...to do with the ways we [ophthalmologists] work and being risk averse”. This point was echoed by other clinical leads who said that when they reviewed follow-up patients’ cases, they found many had been started on
unnecessary treatment; and had been given follow-up appointments when they could have been discharged; or had been followed up more regularly than necessary. This was a particular issue if clinics were run by trainee ophthalmologists who had limited experience, or locums who did not have personal investment or ownership of the service and its capacity issues. The leads pointed out the false economy of extra or weekend clinics to meet capacity if they were run by such staff. In relation to this, one clinical lead said the critical issue was “not more doctors to see more patients, it’s having more doctors to make decisions”.

5.2.66 The importance of consultant input in determining the need for patient follow-ups and their frequency was included in the RCOphth guidance on safe and efficient processes ‘to reduce unnecessarily frequent re-attendances and to increase safe discharge rates’ [51].

5.2.67 One clinical lead illustrated how decision making by a senior clinician could impact on capacity. He informed the investigation that he had the day before reviewed the details of 80 patients whose follow-up appointments were overdue but for whom no clinic appointment was available. From his review, only 17 out of the 80 needed to be seen by an ophthalmologist, the rest being appropriate for review by other members of the multidisciplinary team.

5.2.68 Another clinical lead interviewed by the investigation was about to implement a system in which new patients referred to the HES would be assigned to virtual...
clinics and their results reviewed by a consultant specialising in glaucoma. Thus, at the point of entry to the HES, there would be senior oversight and decision making regarding whether the patient needed to be seen in the HES and, if so, by which member of the multidisciplinary team. The lead planned to measure the number and frequency of follow-ups before and after this initiative to assess its effectiveness.

5.2.69 A study by Broadway and Tibbenham highlighted that junior clinicians are ‘frequently risk averse’ and that involvement of glaucoma specialist consultants in planning patient follow-up can minimise the development of unnecessary clinic appointment backlogs [52]. The aim of the study was to determine whether mass case review, carried out by glaucoma specialist consultants, for patients for whom there was insufficient clinic capacity, could aid reduction of the appointment backlog. Patient hospital notes were reviewed, and a decision made as to whether the planned review was appropriate with respect to timing, clinic type and necessity for follow-up, together with an assessment of whether visual field testing was required. A total of 9,290 cases were included in the study. After consultant review:

- 5,521 patients (59.5%) were kept within the HES and an additional 1,350 (14.5%) had their next appointment delayed.
- 384 patients (4%) were discharged to specialist community glaucoma optometrists and 2,035 (22%) were discharged to standard community
optometrists. Overall, therefore, 26% of patients were discharged from the HES.

• Of the planned 9,290 appointments, simultaneous visual field testing had been requested for 5,393 patients (58%), but after consultant review 3,482 (65%) were considered necessary, reducing the number of required visual field tests by 35%.

5.2.70 The authors concluded that ophthalmology departments experiencing significant clinic appointment backlog issues should consider deploying trained glaucoma specialist consultants to review planned follow-up.

5.2.71 Research by Kwun et al [53] looked at case-management outcome decisions made in virtual glaucoma clinics by three consultants with different levels of experience. The results showed that the overall agreement among the three consultants on recall time for follow-up appointment was low (25%). This may not be surprising because the recommended review intervals suggested by NICE guidance are often wide (see 4.2.21) but it indicates a lack of uniformity of care and service delivery. In addition, unnecessary backlog may be created. The authors conclude that ‘standardized guidance on patient discharge would help to free up capacity’.

5.2.72 Modelling to identify the most efficient and safe way of working may provide evidence of the workforce needed (medical and non-medical) to address demand (see 5.1.46 to 5.1.52 and associated safety recommendation).
Summary

5.2.73 There is a growing shortfall of consultant ophthalmologists. Posts are increasingly filled by locums.

5.2.74 Clinics are often run by locums, trainees or ophthalmologists who are not specialists in glaucoma. Evidence shows that the behaviours of these doctors are often risk averse, resulting in unnecessary, or unnecessarily frequent, follow-up and tests. This in turn creates unnecessary appointment backlogs.

5.2.75 Using specialist glaucoma consultants to review follow-up patients or oversee and scrutinise follow-up decisions by others, can help free up capacity.

5.2.76 Guidance on patient discharge could help standardise behaviours and this, along with other new ways of working, could usefully be included in modelling of service delivery.

5.3 Risk controls

5.3.1 The lack of capacity to meet demand, and harm resulting from delayed appointments, requires risk controls (note 65) to be in place.

5.3.2 In 2009 the National Patient Safety Agency’s Rapid Response Report [9] stated actions required, which were in effect risk controls, such as the development of systems to flag the clinical priority of appointments (see 1.1.10). The need for this risk control was echoed in NICE quality standards and the 2016 commissioning guide for glaucoma [21].
5.3.3 NHS England issued High Impact Interventions (HII) for ophthalmology which required hospital eye services (HES) to develop ‘failsafe prioritisation processes’ and undertake a ‘clinical risk and prioritisation audit’ by March 2019 [12]. The HII contained the following risk controls:

- reviewing all existing patients and stratifying them according to their risk of harm

- prioritising appointments based on risk of harm and intended date for follow-up

- documenting the diagnosis, risk and intended date for follow-up for each patient so that risk and delays can be easily identified

- appointing a ‘failsafe officer’ to ensure these processes are implemented, concerns escalated as needed, and that there is ongoing audit of processes

- ensuring patients are aware of the importance of attending and sending a reminder by text and/or phone a few days before the appointment

- enabling patients at high risk of vision loss, where follow-up is within six weeks, to book their next review appointment before they leave hospital

- not rescheduling appointments without clinician input.

5.3.4 The RCOphth endorsed the risk controls stated in the HII and further detailed the practicalities and processes that HESs should have in place [51].
5.3.5 NHS England/Improvement monitor progress towards the HII as part of their Elective Care Transformation Programme. One of the clinical leads described the measures as “good housekeeping”, allowing a service to be safely and effectively managed. Many of these risk controls were not in place in the majority of HESs when the HII were published. In March 2019, the completion deadline month, NHS England reported (note 66) that 40% of HESs had completed action one (developed failsafe prioritisation processes) and 46% had completed action two (undertaken a clinical risk and prioritisation audit) [54]. By July 2019, 93% of trusts were reported as having completed action one and 91% action two. NHS England/Improvement continues to monitor the progress of trusts with outstanding actions but not those who have reportedly completed them.

5.3.6 The investigation spoke with the Chair and Vice-Chair of the Clinical Council for Eye Health Commissioning (the latter also being the Chair of the London Eye Health Network). They said that clinical review of patients on waiting lists and risk stratification of all those needing to remain under the care of HESs was “essential to determine capacity”. However, they expressed concern about the lack of assurance regarding completion of the HII and lack of involvement of trust boards with the issue of delayed follow-up.

5.3.7 The Vice-Chair shared a letter drafted by the London Eye Health Network which was sent in April 2019 to commissioning leads responsible for trust(s) contracts and quality in London. The letter asked trusts to share the outcomes of their actions with their commissioning leads, and commissioners to share the outcome
of their local eye service demand and capacity reviews (the one HII directed at commissioners) with trusts. He said the request “only had limited impact” and that data was “starting to slowly appear from just a few trusts”. The Chair and Vice-Chair believed that without demonstrable evidence regarding completion of the HII actions, there was little assurance and a risk of very little change happening. They said there was a “lack of accountability” for the sustained change needed and for the measurement of delayed follow-up appointments.

5.3.8 The Chair of Professional Standards for the RCOphth and representatives from the national Elective Care Transformation Programme involved with ophthalmology echoed the concerns about lack of assurance and accountability. There was agreement that without a national target with a contractual requirement for trusts to demonstrate compliance, the required improvement in timeliness of follow-up appointments was unlikely to be realised.

5.3.9 A theme from interviews conducted by the investigation was the time commitment required to carry out the clinical risk and prioritisation audit of existing patients with glaucoma. Although those interviewed agreed it was necessary work, one consultant commented that “doctors need to be seeing patients” and another said undertaking reviews means “time spent managing the crisis rather than transformation”, reflecting the competing pressures on staff time. The Clinical Advisor for GIRFT said that the process
can be semi-automated in HESs that have electronic patient records, considerably reducing the time needed.

5.3.10 If a clinical risk and prioritisation audit identifies an appointment backlog for high-risk patients, NHS England states that HESs ‘should consider evening or weekend clinics or securing external provision to help clear this backlog’ [12]. In the reference event, the size of the backlog would have made it unfeasible for weekend and evening clinics to clear it, and weekend working had stopped because lack of time away from work was having a negative impact on staff. Securing external provision relies on the required service being readily available, and on costs being agreed at a time when finances are stretched. Furthermore, if locums or junior staff run the clinics there can be over-cautious decision making which may exacerbate rather than mitigate the lack of capacity (see 5.2.65 to 5.2.71). The Clinical Advisor for GIRFT was more emphatic, saying that she would rather work through a backlog herself than employ a locum to do this, otherwise “it’s just not worth it”. Evidence from interviews suggested that it was difficult to find quick, effective, solutions to clear backlogs.

5.3.11 Management of capacity, in particular, prioritisation of appointments according to risk and intended follow-up, relies on patient administration systems that are configured to record this information. To be able to report on the percentage of delayed follow-up appointments requires the recommended date for follow-up to be recorded in addition
to the actual appointment date. There is a field on patient administration systems which maps to the nationally collected outpatient Data Set, which trusts have been advised to use to enter the recommended follow-up date (see 5.2.17). Importantly, collection of this data item is not mandated. To be able to report on appointments according to risk stratification would require a further field. However, there is no suitable available field that maps to the national Data Set. Furthermore, experience from collection of the recommended follow-up date suggests that unless data collection is mandated, the likelihood of it being collected is poor (see 5.2.20).

5.3.12 The Lead Information Manager for secondary care at NHS Digital explained that the process of amending clinical administration systems to enable collection of mandated data items is through an Information Standards Notice. She said that the Data Set to be collected centrally (national commissioning Data Set) is currently under review – something that happens once every seven years. The outcome of this will be reflected in an Information Standards Notice to be published in spring 2020. This, therefore, would be an opportune time to include the requirement for a risk rating and recommended follow-up date for each patient, mandating collection of both these data items.

5.3.13 There are specific diagnostic codes that identify which patients have which condition. However, these codes are not routinely used in outpatient services. This means that within the data it is often not
possible to distinguish between patients with glaucoma and those with other ophthalmic conditions requiring follow-up. One way around this would be to mandate the use of diagnostic codes; another would be for the risk rating to have two elements – one to identify the condition and one to stratify risk. For example, for glaucoma, the code could be G1, G2, G3 with G indicating glaucoma and the number indicating the level of risk. This could also help to separate out compliance with the follow-up performance standard for glaucoma patients from those for other ophthalmic conditions.

5.3.14 The Chair of Professional Standards for the RCOphth supported the collection of data about risk. However, she said care would need to be taken to ensure that this did not confuse or inhibit the “more pressing requirement to report nationally in a mandated fashion both the desired date of follow-up and [compliance with] the 25% delay target”.

5.3.15 NHS England acknowledges that there are a number of different electronic patient record and patient administration systems in use across the country and states that trusts ‘need to work with their staff and their patient administration system and clinical system suppliers’ [48].

5.3.16 A recurring theme from interviews was the issue of poor data quality necessitating time-consuming case validation of patients on follow-up waiting lists. Requirements for new data items are likely to be subject to the same quality issues. The involvement of a ‘failsafe officer’ may mitigate this.
5.3.17 The investigation heard that on some electronic patient records or patient administration systems, it was not easy to ‘see’ the data or extract it for monitoring. The difficulty of accessing trust IT support to amend systems and troubleshoot problems was also highlighted. All those interviewed agreed that a dedicated ophthalmology system would “make life much easier” by enabling oversight and easy generation of bespoke reports concerning, for example, delayed appointments and risk stratification. Two of the clinical leads interviewed said they had written business cases to purchase a dedicated ophthalmology IT system but cost restraints meant they had not been approved.

5.3.18 The investigation was told that funding made available to support the national audit on cataracts had allowed trusts to purchase the cataract module of commercially available electronic patient record (EPR) software at a reduced rate. This module enabled all the necessary reporting. A similar software module for glaucoma exists but there is no comparable financial support for its purchase.

5.3.19 In 2018 the RCOphth produced a document outlining two approaches to rating risk of vision loss [55]. The document was for risk rating of ophthalmology patients in general rather than being specific to glaucoma, so does not help with risk stratification of cases within this group.

5.3.20 The document includes the option of identifying only ophthalmology patients who are at high risk and using a red flag
to highlight them, or identifying the level of risk of all patients and highlighting this by colour coding using a red, amber green (RAG) rating – red denoting high risk, amber denoting moderate risk, and green denoting low risk. The document provides guidance on what to take into account when making the judgement but acknowledges: ‘Every patient is different. Some usually low risk conditions can be high risk in some patients, and some potentially high risk conditions can pose little risk in some patients so there is no definitive rule to identify all high risk patients.’ [55] Thus, the senior clinician in charge of the patient’s care must make the final judgement using the same reasoning as for deciding the follow-up interval. The patient in the reference event would fit with one of the considerations included under ‘high risk’ which is: ‘Advanced conditions where small degrees of worsening will make a big difference.’

5.3.21 This investigation focused on glaucoma patients and hence risk rating for this group of patients. The evidence from interviews was that where risk stratification had been carried out, cases were being RAG rated. The level of risk was determined through an individual clinician’s judgement based on a range of factors – such as stage of disease and the latest results of eye tests (for example, visual field loss and intraocular pressure). The rating was being used to inform which member of the multidisciplinary team should see the patient and the nature of the review (for example, virtual clinic or face-to-face appointment).
5.3.22 There are no nationally agreed criteria for risk rating patients with glaucoma. The RCOphth Chair of Professional Standards said that agreeing a set of criteria could standardise practice across HES. She stated that the first step would be to gather information from HES about current practice.

5.3.23 The investigation met with the Clinical Director for Ophthalmology at York Teaching Hospital NHS Foundation Trust. The Trust’s HES had risk rated patients with glaucoma. A RAG rating was applied retrospectively to each patient within the whole glaucoma cohort, using a computer algorithm, predominately based on previous interval and frequency of follow-up. When patients were then seen in clinic this risk rating was updated and entered into the patient administration system by the ophthalmologist. In another trust the risk rating was written onto an appointment request slip which the patient handed in to reception.

5.3.24 The Clinical Director for Ophthalmology at York said that he and the Directorate Manager had worked with the Trust’s IT team to set up the ‘Olympic risk stratification tool’. This tool assesses compliance with the performance measure for follow-up appointments – that is, whether the appointment occurs within no more than an additional 25% of the recommended follow-up time. A gold, silver or bronze rating is assigned automatically without any manual input (note 67).

5.3.25 The Clinical Director explained that reports can be easily generated from the patient
administration system and are used to inform weekly meetings regarding service capacity and demand. He said that the clinical risk stratification and Olympian rating combined had made it possible to know the scale of the backlog problem (note 68) or organisational risk (ability to offer patients timely and appropriate follow-up) and the amount of clinical risk (patient disease status). This had allowed the service model to be completely redesigned. The model could be planned and adjusted based on clearly evidenced clinical need and capacity requirements. For example, patients whose risk of vision loss was RAG rated as green were assigned to virtual clinics; patients rated as amber were assigned to clinics with consultant oversight, and those rated red were assigned to consultant-led clinics. He said the Olympian rating highlights the capacity requirements and where extra capacity is needed while ensuring priority for patients at highest risk of vision loss. Furthermore, he said the data provides the evidence needed to support requests for additional resource and allows the risk of harm to be known when resources are not granted. The Clinical Director summed up the benefits of the information available, saying: “We are in a data and technology rich world, we need to use it as our friend.”

5.3.26 The Clinical Director said it had been “very easy” to set up the Olympian risk stratification tool and that they were able to start generating reports within about two weeks of speaking with the IT team. He thought it would be possible to replicate the tool in other trusts. In addition, within his own organisation,
consideration was being given to implementation of the tool across all sub-specialties within ophthalmology, and to assessing its application to, and potential impact on, other outpatient services.

5.3.27 The Clinical Advisor for GIRFT echoed comments by other clinical leads about the importance of identifying the patients with glaucoma who are at highest risk of sight loss and prioritising them for appointments. She pointed out that risk stratification is based on clinical judgement informed by the stage of disease severity and progression (based on recent eye test results) at the time the patient is seen. The follow-up interval is also a matter of judgement guided by the NICE parameters [8]. However, there is significant leeway in the NICE parameters; for example, the timescale for review for a patient where there is ‘no progression detected and high clinical risk’ is suggested as between six and 12 months. Across a caseload of thousands of patients, choosing six rather than 12 months would have a large impact on an appointment backlog.

5.3.28 NICE guidance states that if there was a sensitive and specific tool to predict progression to sight loss it would ‘be useful for both patients and healthcare professionals. People at higher risk of sight loss could have more frequent testing and perhaps more intensive treatment, whereas people at lower risk could have less frequent assessments and potentially less intensive treatment’ [8]. Currently such a tool does not exist.
5.3.29 The Clinical Advisor for GIRFT said an ideal tool would be an algorithm based on clinical markers (already available to a limited extent in one of the commercially available EPR software packages) which could be used to predict risk of future sight loss. This would mean that risk of progression could be picked up earlier than happens currently. The model could also be used to determine optimum interval for follow-up. The Clinical Advisor pointed out that there is considerable clinical data available which, if appropriately analysed, could inform development of the model.

5.3.30 The Clinical Advisor said that research is being carried out in this area, for example, at Moorfields Eye Hospital NHS Foundation Trust and in Bristol. She commented that the funded research at Moorfields was focused on fine-tuning individual risk rating, whereas the work in Bristol focused on testing a risk formula in large numbers of cases to consistently be able to identify and distinguish between high-risk and low-risk cases. The objective is that individual trusts will be able to use this formula to run large risk reports and thereby organise their services accordingly.

5.3.31 The investigation met with the consultant in Bristol (also a professor at the University of Bristol) who is leading this work. He said that he had applied criteria based on visual fields and other clinical data in order to risk-stratify patients seen in Bristol Eye Hospital over the last three years. The consultant has links with a scientific researcher who has been devising analysis tools to predict speed of disease progression. The consultant said
his work had provided “proof of concept” which would need to be tested on a larger scale to assess its reproducibility and workability before potentially being adopted nationally.

5.3.32 The consultant’s choice of criteria was based on his personal expertise and informed by existing evidence. However, he pointed out that before the tool was considered for national use, the criteria to be used should be agreed by a consensus of the glaucoma community. He also said that automation was only feasible in HESs that had electronic medical records which included visual field data. If the evaluation of the model was positive, the consultant said it would have the potential to automate the detection of high-risk cases across entire services, stating: “This has the potential to revolutionise the way we organise and run glaucoma care.”

5.3.33 The investigation explored how the research needed to assess reproducibility and workability of the model could be funded. It contacted the International Glaucoma Association (IGA) - the charity for people with glaucoma. It provides information, literature and advice, and funds essential research to prevent unnecessary loss of sight through early detection, diagnosis and treatment. The Chief Executive of the IGA was familiar with the work of the consultant in Bristol and thought trustees may look favourably on an approach for further support.

5.3.34 The consultant’s risk stratification criteria identified that 6.75% of patients in the total glaucoma cohort reviewed were in the high risk category. Approximately 15% were low risk and could be discharged from the HES with follow-up in the community.
The review identified that the majority (76%) of patients were in the medium risk group. Of these, some could be seen by appropriately accredited optometrists and some would need to remain under the care of an ophthalmologist.

**Summary**

5.3.35 Risk controls are required to manage capacity issues effectively and reduce the risk of harm.

5.3.36 In some trusts there are challenges with IT systems which make it difficult to set up effective risk controls. A dedicated ophthalmology system would be helpful but there are no national resources to support the purchase of these.

5.3.37 Risk stratification of patients is carried out by ophthalmologists using their clinical judgement, informed by the latest eye test results. Agreed criteria would allow standardisation of risk stratification across HES. One way to allow identification of patients with glaucoma would be the use of a code that identifies glaucoma as well as patients’ level of risk.

5.3.38 Mandating the recommended follow-up date and risk stratification would require the inclusion of these data items in an Information Standards Notice.

5.3.39 Data regarding delayed follow-up combined with risk stratification can be used to create automated reports, which can provide the foundation for effective risk control.

5.3.40 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 the reproducibility and workability of the model. If positively evaluated, the model would support proactive planning of service delivery and effective use of resource based on clinical need.

HSIB makes the following safety recommendations

Safety recommendation 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 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 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.
NHS care is provided in two main ways: primary care (GPs and community services) and secondary care (hospitals and specialists).


Interviews took place by telephone (5 participants), in a group setting (3 participants) or face to face (12 participants) at the International Glaucoma Association patient conference on 20 September 2019.

The Patient Advice and Liaison Service (PALS) provides a point of contact for patients, their families and their carers who need help resolving concerns or problems or with health-related questions.

NICE Quality Standard 1 concerns referral. The quality measure is: ‘Proportion of adults with signs of possible glaucoma on a routine sight test who had additional tests before referral for further investigation and diagnosis of chronic open angle glaucoma or related conditions.’

Information provided in the joint submission to HSIB from the Association of Optometrists and Local Optical Committee Support Unit.

The term ‘false negative’ refers to those patients seen by (accredited) community optometrists and not referred to HES but who should have been according to the referral criteria in place.

The review was commissioned as part of the UK National Screening Committee’s regular review cycle of all policies.

The findings of the evidence review were out for consultation during HSIB’s investigation.

Of note, most patients’ glaucoma is ‘stable’ for a time-limited period. Over time, the condition usually gets worse and the intervention required may change, hence the need for ongoing monitoring.
The existing access standards, or performance targets, for elective care (care that is planned, rather than emergency care) were introduced in 2009. In 2018, following the publication of the NHS Long Term Plan, the national medical director was asked to undertake a clinical review of the standards with a view to updating and supplementing them as necessary.

The committee’s purpose is to review population eye health and wellbeing at national and local level, and present key evidence-based indicators to monitor quality and outcomes from eye health and care services.

The Portfolio of Indicators for Eye Health and Care sets 95% as the ‘achievable standard’. The ‘minimum standard’ is 85% of hospital appointments to occur within no more than an additional 25% of the intended follow-up period.

Providers includes trusts (approximately 120) and independent providers of NHS-funded eye services – for example, community optometrists, private healthcare organisations and so on.

Information provided at a conference call with representatives of NHS Digital and other stakeholders on 4 September 2019.

The risk categories are defined as follows: risk category 1 – risk of irreversible harm or significant patient adverse outcome if the patient target date is missed; risk category 2 – risk of reversible harm or adverse outcome if the patient target date is missed; risk category 3 – no risk of significant harm or adverse outcome.

The online hub is called EyesWise. As well as providing resources and examples of new ways of working, the hub provides a way to collaborate and to communicate with others working to transform ophthalmology services. It can be found at: https://future.nhs.uk/connect.ti/ECDC/view?objectId=14240112

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https://www.bbc.co.uk/news/uk-wales-48585767
NHS commissioners buy services from NHS providers of care. The national tariff consists of a set of prices and payment rules, which aim to support the delivery of efficient, cost-effective care to patients. NHS England/Improvement are responsible for setting the national tariff.

This is not the same in, for example, Northern Ireland, which does not have a tariff system and where pricing is the same for new and follow-up appointments.

For example, the Commissioning for Quality and Innovation (CQUIN) scheme. This is a system introduced in 2009 to make a proportion of healthcare providers’ income conditional on demonstrating improvements in quality and innovation in specified areas of care.

Non-mandatory prices are published to support the sector to negotiate prices locally. They are intended as a starting point.

In their submission to HSIB, the Association of Optometrists and Local Optical Committee Support Unit included examples of community optometry services for glaucoma referral filtering and monitoring which had saved hospital appointments and so helped relieve capacity.

The model of care developed in Belfast which has enabled follow-up demand to be met does not exist in other areas of Northern Ireland, although the plan is to replicate it nationally.

The workforce census was sent to the 135 trust and health boards providing ophthalmology in the UK. There was a 75% response rate.

For a definition of risk controls see 3.4.2.

The figures were reported during a webinar on 19 March 2019.
67 A gold rating means a patient has been given an appointment within the requested timescale; a silver rating means an appointment has been given within the 25% tolerance of the requested follow-up timescale; and a bronze rating means an appointment has been given outside the 25% tolerance of the requested follow-up timescale.

68 In common with other trusts, the backlog ran to thousands of appointments.
6 Summary of findings and safety recommendations

6.1 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 optometrists. 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.

• 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 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:
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Ophthalmologists and patient administration system suppliers.

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**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.
The investigation reviewed incidents relating to issues with ophthalmology monitoring and follow-up processes reported to the national Strategic Executive Information System (StEIS). An initial review identified 158 incidents reported as occurring between 1 April 2017 and 31 December 2018. Eighteen of these reports related to groups of patients and/or incidents; the exact number of patients affected was not given. A further review, narrowing the search criteria, identified 80 incidents reported as occurring between 1 April 2017 and 31 December 2018 that specifically involved glaucoma outpatient follow-up.

The following search criteria were used to generate the StEIS data used in the report:
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</tr>
<tr>
<td></td>
<td>Treatment delay meeting SI criteria</td>
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8 References


[34] UK National Screening Committee. (n.d.) Current UK NSC Recommendations-Glaucoma. [Online] Available at: https://legacyscreening.phe.org.uk/glaucoma


FURTHER INFORMATION

More information about HSIB – including its team, investigations and history – is available at www.hsib.org.uk

If you would like to request an investigation then please read our guidance before submitting a safety awareness form.

@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.

CONTACT US

If you would like a response to a query or concern please contact us via email using enquiries@hsib.org.uk

We monitor this inbox during normal office hours – Monday to Fridays (not bank holidays) from 0900hrs to 1700hrs. We aim to respond to enquiries within five working days.

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