



# EyesWise 100 Voices

Final Report (v1.3)

October 2020

NHS England and NHS Improvement



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**Please note:**

This work was completed before the outbreak of COVID-19. Whilst many of the recommendations in this document there are still applicable for the improvement of patient experience it does not mention the new measures to ensure all settings are, where practicable, COVID-secure such as using social distancing. For more information please consult COVID-19: infection prevention and control (IPC) guidance <https://www.gov.uk/government/publications/wuhan-novel-coronavirus-infection-prevention-and-control>

# 1. Executive summary

1. The NHS Long Term Plan (LTP)<sup>1</sup>, identified the need to undertake radical changes to the provision of elective care services across all specialties. There are nearly eight million appointments every year in hospital eye services in England, making ophthalmology one of the largest outpatient specialties. It continues to see significant growth in demand which is putting ever greater strain on community and hospital eye services.
2. In 2018 the All Party Parliamentary Group (APPG) on Eye Health and Visual Impairment undertook an inquiry into the commissioning and planning of eye care services in England, given concerns around capacity and its impact on patient care.<sup>6</sup> As a result of this and the recognition of the need to undertake transformation work across ophthalmology services, the EyesWise work stream was set up within the NHS England & Improvement (NHSE&I) Elective Care Transformation Programme (ECTP) to take this forward.<sup>7</sup>
3. A key objective of the programme has been to understand the experiences of patients and service users. Therefore, the 100 Voices engagement campaign was established. It aimed to capture at least 100 stories from patients, carers and staff; both to celebrate success, and understand where services could do better to support continued improvement. It commenced in April 2019, with the support and engagement of national charities including the Royal National Institute for Blind People (RNIB), the Macular Society, Royal College of Ophthalmologists (RCOph), and the International Glaucoma Association.
4. Patients and staff were able to upload and send their stories to NHS England via a secure online portal; and efforts were made to ensure that different communities, including people with learning disabilities, had the opportunity to give their stories if they wanted to. Events were also held to give patients, service providers and commissioners the opportunity to consider and comment on the general findings of the project.
5. 277 submissions were received as part of the campaign, from patients, carers/relatives and staff. Stories varied in length and covered a wide range of different eye conditions. Respondents came from a range of different age

groups with the majority being over 65. Analysis of the stories received shows a range of both positive and negative experiences. It appears that more of the stories received were either positive in nature (42%) or included positive as well as negative elements (31%). Roughly a quarter (27%) of the stories were wholly negative in nature. Stories highlighted a variation in experiences even within a provider. This strongly indicates that there remains variation in practice and experience both across and within providers.

6. The key themes which have emerged from analysis of the stories were:

Key Themes
Appointments
Deterioration due to delays
Continuity and consistency of care
Staff attitudes, empathy and understanding
Communication and access to information
Support for patients (including ECLOs)
Transport and access

7. Appointments emerged as the major theme, being mentioned in at least 25% of stories. These incorporated a number of sub-themes, including: long waits for appointments; difficulties making changes to appointments; cancellations (by the hospital eye service); timing of appointments; long waiting times during the appointment; and the environment at the appointment (not being suitable for those with visual impairment or blindness).
8. The report makes a number of recommendations. These are summarised in section 1.1 below (these are also summarised by organisation type in section 1.2).

## 1.1 Summary of Recommendations

Recommendations	
1.	Local health systems (both commissioners and providers of eye-care services) should make use of the Patient Journey Map created as part of the 100 Voices Project to assist in engagement, developing thinking and service improvement. <sup>12</sup>
2.	Providers of eye-care services should explore ways to make it easier for patients to make and communicate regarding appointments.
3.	Providers of Hospital Eye Services should comply with and fully implement NICE Quality Standard 180 <sup>16</sup> and give patients the opportunity to discuss their diagnosis, prognosis and management.
4.	Providers of eye-care service should make use of patient activation tools to support patients in self-managing their condition.
5.	Providers of eye-care services and those supporting patients with eye conditions should provide appropriate training, education and support tailored to a patient's activation level. This should particularly target support and interventions at people with lower activation levels and disadvantaged groups to address health inequalities and support them to self-manage.
6.	Providers of eye-care and support services (including charities, third sector organisations and carers) should provide outreach and education to ensure that they support people to prevent potential future sight loss.
7.	NHSE&I and local health systems (both commissioners and providers of eye-care services) should improve local understanding of the patient experience of eye-care services through the regular collection of patient feedback. This should be used to improve and develop services. <sup>10</sup>
8.	All providers of eye-care services should ensure full compliance with the Accessible Information Standard. <sup>19</sup>
9.	All providers of eye-care services should take steps to ensure that their services (including staff, communications and clinic space) are accessible to those with learning disabilities.
10.	Providers of Hospital Eye Services should comply with and implement NICE Guideline 81: for the diagnosis and management of Glaucoma. <sup>21</sup>
11.	Providers of Hospital Eye Services should implement failsafe prioritisation processes and report on performance against these.

## Recommendations

12.	NHS Digital and NHSE&I should work to include provision for identifying, prioritising and monitoring patients at risk of developing sight loss within the national Commissioning Data Set.
13.	Local health systems (both providers and commissioners of eye-care services) should consider eye services from the patient perspective, ensure that the patient voice is properly represented on local eye health groups, and involve visually impaired people in the design/redesign of eye-care service facilities.
14.	Local health systems (both commissioners and providers of eye-care services) should consider alternative models of delivering services.
15.	NHSE&I should continue to prioritise the development, redesign and transformation of ophthalmology services.
16.	All providers of eye-care services should take steps to fully implement ECLOs within their services.
17.	Providers of eye-care services should look to upskill existing staff where appropriate.
18.	Sight awareness training should be mandatory for staff involved in the provision or commissioning of eye-care services. Providers of eye-care and support services should therefore take steps to provide this for their staff; working with the third sector (RNIB and others).
19.	Local health systems (both commissioners and providers of eye-care services) should ensure that ophthalmic pathways of care are simple, easy to understand and consistent across the system and are communicated clearly to staff, primary care providers and patients. <sup>10</sup>
20.	Providers of eye-care services and other organisations providing support to those with eye conditions (including charities and third sector organisations) should ensure that consistent information on available services is signposted.
21.	Providers of Hospital Eye Services should work with their commissioners and community services (as appropriate) to implement appropriate referral and triage systems for referrals into secondary care to reduce waiting times.

## 1.2 Recommendations by Organisation Type

Local Health Systems	Providers
<p>Local health systems (both commissioners and providers of eye-care services) should make use of the Patient Journey Map created as part of the 100 Voices Project to assist in engagement, developing thinking and service improvement.<sup>12</sup></p>	<p>Providers of eye-care services should explore ways to make it easier for patients to make and communicate regarding appointments.</p>
<p>NHSE&amp;I and local health systems (both commissioners and providers of eye-care services) should improve local understanding of the patient experience of eye-care services through the regular collection of patient feedback. This should be used to improve and develop services.<sup>10</sup></p>	<p>Providers of eye-care services and those supporting patients with eye conditions should provide appropriate training, education and support tailored to a patient’s activation level. This should particularly target support and interventions at people with lower activation levels and disadvantaged groups to address health inequalities and support them to self-manage.</p>
<p>Local health systems (both providers and commissioners of eye-care services) should consider eye services from the patient perspective, ensure that the patient voice is properly represented on local eye health groups, and involve visually impaired people in the design/redesign of eye-care service facilities.</p>	<p>Providers of eye-care service should make use of patient activation tools to support patients in self-managing their condition.</p>
<p>Sight awareness training should be mandatory for staff involved in the provision or commissioning of eye-care services. Providers of eye-care and support services should therefore take steps to</p>	<p>Providers of eye-care and support services (including charities, third sector organisations and carers) should provide outreach and</p>

Local Health Systems	Providers
provide this for their staff; working with the third sector (RNIB and others).	education to ensure that they support people to prevent potential future sight loss.
Local health systems (both commissioners and providers of eye-care and support services) should ensure that referral to all relevant support services is straightforward and timely. <sup>10</sup>	All providers of eye-care services should ensure full compliance with the Accessible Information Standard. <sup>19</sup>
Local health systems (both commissioners and providers of eye-care services) should ensure that ophthalmic pathways of care are simple, easy to understand and consistent across the system and are communicated clearly to staff, primary care providers and patients. <sup>10</sup>	Providers of eye-care services and other organisations providing support to those with eye conditions (including charities and third sector organisations) should ensure that consistent information on available services is signposted.
Local health systems (both commissioners and providers of eye-care services) should consider alternative models of delivering services.	All providers of eye-care services should take steps to ensure that their services (including staff, communications and clinic space) are accessible to those with learning disabilities.
	All providers of eye-care services should take steps to fully implement ECLOs within their services.
	Providers of eye-care services should look to upskill existing staff where appropriate.
	Providers of Hospital Eye Services should comply with and fully implement NICE Quality Standard 180. <sup>16</sup> and give patients the opportunity to discuss their diagnosis, prognosis and management.
	Providers of Hospital Eye Services should comply with and implement NICE Guideline 81: for the diagnosis and management of Glaucoma. <sup>21</sup>



Local Health Systems	Providers
	<p>Providers of Hospital Eye Services should implement failsafe prioritisation processes and report on performance against these.</p>
	<p>Providers of Hospital Eye Services should work with their commissioners and community services (as appropriate) to implement appropriate referral and triage systems for referrals into secondary care to reduce waiting times.</p>

## 2. Background

1. The purpose of this report is to provide a summary of the findings of the 100 Voices campaign, undertaken as part of the NHS England and Improvement (NHSE&I) Elective Care Transformation Programme (ECTP) EyesWise Ophthalmology work stream.
2. The NHS Long Term Plan (LTP)<sup>1</sup> (and the Five Year Forward View<sup>2</sup> before it), identified the need to undertake radical changes to the provision of elective care services. In particular, the need to improve waiting times, make more efficient use of all available capacity, and to improve outcomes. The ECTP was established in 2017 to lead transformational change and share best practice across the country to deliver improved elective care and outpatient services across a range of specialties.<sup>3</sup>
3. There are nearly eight million appointments every year in hospital eye services in England, making ophthalmology one of the largest outpatient specialties. Ophthalmology continues to see significant growth in demand which is putting ever greater strain on community and hospital eye services. Indeed, an aging and increasingly diabetic population, along with the development of new therapies and treatments for eye conditions means that demand for ophthalmic services is predicted to increase by 25% over the next 10 years.<sup>4</sup>
4. In 2018 the All-Party Parliamentary Group (APPG) on Eye Health and Visual Impairment undertook an inquiry into the commissioning and planning of eye care services in England, based on the growing body of evidence at the time that there were significant capacity issues in eye care services that were negatively impacting upon patient care. Data from the British Ophthalmological Surveillance Unit (BOSU) presented to the Inquiry highlighted that up to 22 people per month were experiencing permanent and severe visual loss due to health service initiated delays.<sup>5</sup>
5. This report<sup>6</sup> made a number of recommendations for statutory bodies, including NHS England. Key recommendations include:
  - i) To bring ophthalmology fully within the NHS transformation programme whilst adequately funding service redesign.

- ii) For NHS providers to ensure the eye care pathway is clear for those responsible for managing patient care and effectively communicated to patients.
6. As a result of the APPG report and the recognition of the need to undertake consistent transformation work across ophthalmology services, the EyesWise work stream was set up within the NHSE&I ECTP to take this forward.<sup>7</sup>
  7. Since April 2018, a comprehensive programme of work has been undertaken by NHSE&I, in collaboration with Getting It Right First Time (GIRFT) and the Royal College of Ophthalmologists (RCOphth), across the country to redesign and improve eye care services. This has aimed to improve the consistency of service provision and to streamline and speed up outpatient services and treatment for those at highest risk of sight loss. Its aim has been to ensure that people in England who need consultant-led eye care get it as quickly as possible, and that others are spared the need to attend specialist eye clinics but can instead access care and support in community settings.
  8. Work has included the development of High Impact Interventions to support hospital eye services across England to act to ensure the timely assessment and follow-up of those most at risk of sight loss due to chronic eye conditions. Similarly, CCGs have been supported to undertake eye health capacity reviews to assess the demand for ophthalmology services in their population and the capacity of services to deliver them. An EyesWise Virtual Development Collaborative was also established to support a number of local systems to introduce virtual ophthalmology clinics. This learning is now being consolidated and shared with other systems to aid them in the development of alternatives to face-to-face clinics.
  9. A key objective of the EyesWise transformation programme has been to understand the experiences of patients and service users in order to identify best practice and areas which still need improvement.
  10. The EyesWise programme established the 100 Voices campaign with the aim of capturing at least 100 stories from patients, carers and staff in order to both celebrate success, and understand where services could do better in order to support continued improvement.

11. The following sections of this report summarise the work undertaken as part of this campaign and its subsequent findings. It then makes several recommendations based on these as to how services could be improved.
12. It is important to acknowledge that the 100 Voices project and wider EyesWise transformation programme have been undertaken within a broader context of work to develop and transform ophthalmology services in England. This includes the recent Health Service Investigation Branch (HSIB) investigation and report into the lack of timely monitoring of patients with glaucoma<sup>8</sup>; the GIRFT report into improving ophthalmology services<sup>9</sup>; and the upcoming NHS RightCare Eye Health Toolkit<sup>10</sup>.
13. The findings of this report should be taken and understood within the context of this wider work. In formulating its recommendations, this report has also drawn upon these other publications in order to develop a robust set of recommendations for improving services. Where other work has been drawn upon this is referenced, as appropriate.

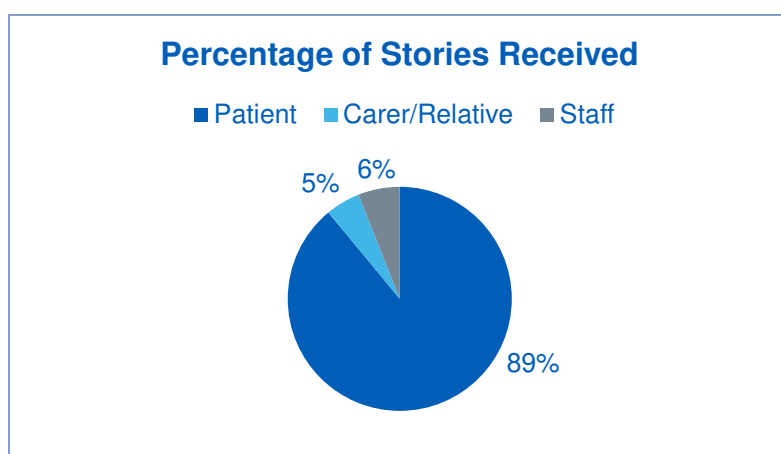
# 3. The approach

1. The EyesWise 100 Voices campaign commenced in April 2019. It sought to capture and share patient experiences of ophthalmology services; and to give hospital eye services and CCGs the opportunity both to celebrate success (highlighting achievements to staff, colleagues, patients and the wider community), and to understand where services could do better (to support improvement); and so to inform the future commissioning, planning, provision and redesign of eye care services.
2. The Patient Experience Network (PEN) were commissioned to run the campaign on behalf of NHSE&I; and national charities including the Royal National Institute for Blind People (RNIB), the Macular Society, RCOphth, and the International Glaucoma Association have been involved and have been active participants from the start.
3. The key aims of the project were:
  - i) To enable patients, carers and staff to share their experiences of ophthalmology services since April 2018 with providers and commissioners of hospital eye services and the public, celebrating success and supporting further transformation. The project had an objective in this regard to capture at least 100 stories from patients, carers and staff by April 2020. Data captured was to include both functional and emotional elements of experience, together with the wider holistic effects of sight loss or impairment.
  - ii) To ensure diversity of response so that different communities, including people who did not have English as their first language and people with mental health problems or learning disabilities, had the opportunity to give their stories if they wanted to.
  - iii) To provide guidance to local systems on making the best use of the patient perspective in their decision making; and to encourage the sharing of changes made with patients and the Elective Care Transformation Programme.

4. Communications were cascaded to providers to provide guidance on how to capture patient stories. Charities also played a key role in raising awareness amongst patients/the public and supporting individuals to tell their stories. All systems were asked to identify two or three patients who would like/be able to tell their stories of using hospital eye services. Posters were also put up in ophthalmology clinics to advertise the campaign and to ask for stories. Efforts were made to ensure that different communities, including people with mental health problems or learning disabilities, had the opportunity to give their stories if they wanted to.
5. Patients and staff were able to upload their stories via a secure online portal. This provided a web form for individuals to provide a written story, or the capability to upload an audio or video recording. Additional video and audio opportunities were provided by engaging with specialist eye services, charities and other organisations who engage with users of hospital eye services. This included the RNIB, Moorfields, Manchester Eye Hospital and SeeAbility amongst others. The stories captured have been reviewed, collated and uploaded to the Elective Care Community of Practice (as a hosting site) to be shared as a resource to inform the future development and commissioning of services.<sup>11</sup>
6. Patients, service users and carers attended an event held in January 2020. The event gave patients the opportunity to share their experiences of hospital eye services and to consider and comment on the general findings of project to that point. The attendees mapped the current patient pathway from both a functional (what happens) and emotional (how it makes an individual feel) perspective. They considered the 'ideal patient journey' and identified ideas and opportunities for improvement. This produced a Journey Map<sup>12</sup> which has also informed this report and is a key output for commissioners and providers to consider in redesigning services.
7. Commissioners and providers of hospital eye services were also given the opportunity to consider the findings from the 100 Voices campaign at an event held in early March 2020. They had the opportunity to identify issues with current services, suggest improvements and make commitments to changes that they would like to make to their local services. These outputs have also been made available on the Elective Care Community of Practice.<sup>13</sup>

## 4. Who took part?

1. In total, 277 submissions were received as part of the campaign:
  - 231 written submissions (to the NHS 100 Voices portal)
  - 35 video and audio recordings
  - 11 telephone interviews
2. Demographic data was analysed quantitatively to understand the spread of stories across services, regions and groups. Qualitative data was analysed thematically to identify key themes and areas for improvement.
3. The pie chart below shows how these stories were split between those from patients, carers or relatives and staff. The vast majority of stories captured were from patients and service users.



4. Most stories received (83%) were 'full stories' (i.e. those of a reasonable length which outlined experiences in some detail). However, a substantial minority of stories received were soundbites (around 1-3 lines of information). It should be noted that these are still important and have been fully considered within this analysis as they at least outline whether an individual had a positive or negative experience of care.
5. In terms of the specific eye conditions which were captured within the stories, the respondents whose stories were captured included a wide range of

different eye conditions. The table below summarises the main conditions which were captured within the stories.

Condition	%
Cataracts	28.7%
Macular degeneration (all types)	15.2%
Glaucoma	14.3%
Other (*these are listed below)	11.1%
Detached retina	4.2%
Diabetes	3.4%
Toxic retinitis, retinitis pigmentosa and other retinal problems	3.0%
Injury/accident	2.0%
Posterior vitreous detachment	1.2%

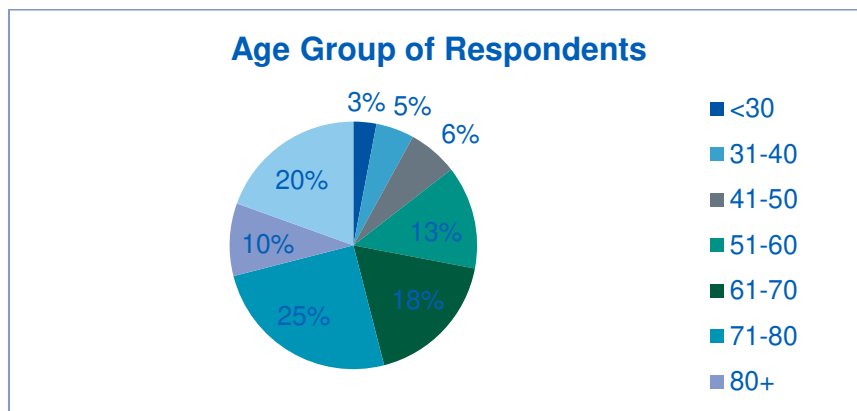
\*Other as a group covered a broad range of conditions which separately were represented in too small a sample of stories to be significant statistically. These included: Allergic eye disease, Blepharitis, Burst blood vessel, Convergence insufficiency, Corneal oedema, disability, hard corneas, Keratoconus, Lazy eye, long sightedness, Macular hole, Marfan syndrome, Meburnitis, Myopic choroidal neovascularisation, Negative dysphotopsia, neurological conditions, Night blindness, Nystagmus, Optic atrophy, Optic nerve drusen, Rhabobmyosarcoma, Ripped cornea, scarring, Severe ocular surface disease, Sjorgrens syndrome, Stevens Johnson syndrome, Tunnel vision, Uveitis.

NOTE 1 16.9% of overall respondents did not give (or from their submissions it is not possible to identify) details of their condition.

NOTE 2 Of those respondents that gave details of their condition, 22% identified that they had multiple conditions.



6. In terms of the organisational and geographical spread of responses, in total responses were received from 66 hospital eye services. This represents 55% of the total 120 hospital eye services in England. All regions were represented. Buckinghamshire Healthcare NHS Trust provided a disproportionately high number of submissions (63) when compared with other Trusts. These stories were therefore also analysed separately to assess for any potential bias introduced to the overall dataset. Analysis shows that there were a higher proportion of positive stories, and a higher proportion of soundbite/1 liner stories, compared with overall.
7. The pie chart below provides a breakdown of the age groups of respondents, showing that respondents came from a wide range of different age groups. The majority of respondents (52.5%) were in the 65+ age groups. Overall, 19.5% of respondents did not wish to give their age.

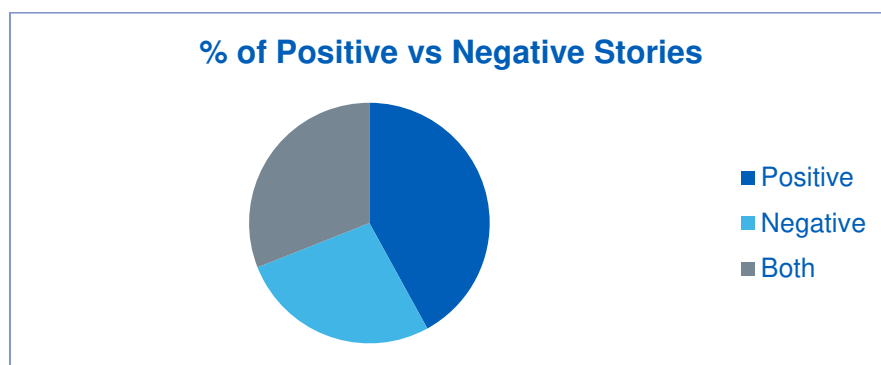


8. With regards to ethnicity, overall the vast majority of responses received (86.1%) identified themselves as being from a White background. In total less than 5% (4.8%) of respondents identified as being from a BAME (or any other minority) ethnicity. 9.1% of respondents either did not provide or actively declined to give details of their ethnicity. The table on the next page provides a more detailed breakdown of the ethnicity of respondents.

Ethnicity	%
Asian/Asian British: Any other Asian background	0.43%
Asian/Asian British: Indian	0.87%
Asian/Asian British: Pakistani	0.43%
Black or Black British: Black - Caribbean	0.87%
Mixed: Any other mixed background	0.43%
Mixed: White and Asian	0.43%
Other ethnic group: Any other ethnic group	0.87%
Prefer not to say	3.91%
White: Any other White background	0.87%
White: Irish	1.74%
White: Welsh/English/Scottish/Northern Irish/British	83.48%
Not given	5.22%
Black or Black British: Black - African	0.43%

## 5. Key findings

1. The key messages and findings from analysing the captured stories are summarised in this section. The full analysis and report (including a number of in-depth case studies) produced by PEN is available on the Elective Care Community of Practice.<sup>14</sup>
2. Analysis of the stories shows a range of both positive and negative experiences. It appears that more of the stories received were either positive in nature (42%) or included positive as well as negative elements (31%). Roughly a quarter (27%) of the stories were wholly negative in nature. This is highlighted by the pie chart below. This suggests that there is a significant amount of good practice and success to celebrate within hospital eye services in addition to the undoubted areas which need improvement.



3. Having said this, where there were a reasonable number of stories for an individual Trust (for the purposes of this report 10 is considered reasonable), it is noted that the stories highlighted a variation in experiences even within a provider. No provider received wholly positive or wholly negative comments. This strongly indicates that there remains variation in practice and experience both across and within providers and that there is therefore room for improvement across the board.
4. The key themes which have emerged from analysis of the stories are summarised in the table below. These are then considered in more detail in the rest of this section. A selection of quotes (both positive and negative) from the submitted stories are included to illustrate each theme.

Key Themes
Appointments*
Deterioration due to delays
Continuity and consistency of care
Staff attitudes, empathy and understanding
Communication and access to information
Support for patients (including ECLOs)
Transport and access

\*Note: Appointments was the major theme which emerged and is split into several sub themes as explored below.

## 5.1 Appointments

- Appointments were mentioned in more stories than any other subject – at least 25% of them – even when the story was largely positive. However, mentions of appointments were predominantly negative, were not particularly condition or geographically concentrated, and centred around the following issues.
- Long waits:** Patients and service users repeatedly complained about long waits for appointments. Whether this was for the first appointment or follow-up appointments, for first operations but particularly for second operations. Length of time between appointments was exacerbated by the inability to get hold of people with responsibility for booking appointments (separate issue below), either to change the appointment or simply find out when it was going to be.

**‘..my appointments have never been when they were supposed to be, they say 9 months that turns into a year, I’m still waiting now for follow up appointment that should have been in July/August’**

**'I was supposed to have an appointment 3-4 months later. My appointment was finally 18 months later'**

**'I am rarely seen at the interval the consultant requests. Recently, I was told he'd see me in 4 months but didn't receive an appointment until 7 months.'**

7. **Making changes:** Patients and Service users highlighted issues contacting hospitals or people responsible for making appointments, either to make changes or simply check when they were scheduled. In many cases the only reason for a call was that patients had not received an appointment when one was due and were concerned their condition would deteriorate or that they had been lost in the system.

**'Waited long time, impossible to contact secretary or consultant'**

**'Trying to get an appointment is very bad, you are waiting longer and longer for check-ups. Also phoning the eye unit to chase up appointments is becoming harder as you can't get any answer even if you call at different times of the day.'**

8. **Cancellations:** One concern raised by patients was that, whilst they had to wait months for appointments, hospitals could cancel appointments at short notice without any apparent empathy or understanding. Whilst this may not always be the case this is how it is often perceived by patients. Reduction of hospital-initiated cancellations is also a key area of focus for the NHS LTP.

**'Less than 24 hours before my procedure, I received a short, curt phone call saying my operation had been cancelled as there were too many patients. It was a dry and routine-like voice at the end of the phone. A voice that wanted to spill out the words and be gone and onto the next unsuspecting soul. It was a call that left me too stunned to react.'**

9. **Timing:** The timing of appointments is another concern. There were numerous mentions of lack of consideration for sight impairment, and the issues that brings, in the timing of appointments. This included transport issues (long/complex journeys, public transport, reliance on family/friends);

conditions which made travelling in the dark difficult; the best/worst time of day for the condition. Good practice was identified as being allowed to make appointments before leaving the clinic, having a manned telephone line, being consulted about/agreeing a date before being sent confirmation.

**‘Booking appointments are always difficult, it always involves several phone calls or emailing consultant secretaries. Because we live nearly 2 hours away, we have to know in advance for childcare and to be prepared.’**

**‘Clinics should be held in the morning, people with Glaucoma often struggle with night-time driving and pressures can be higher in the morning.’**

- 10. Waits during the appointment:** In addition to long delays between appointments patients also commented on long waiting times once they arrived for appointments, this especially applied to eye clinics/check-ups (macular, glaucoma, cataract) but as these were the most prevalent conditions (almost 60% of the total) this is perhaps not surprising. There are Trusts who have made recent changes and are now getting it right (for those who submitted at least) and they were commended by patients, particularly Northwich Park clinic, East Kent and Nottingham University. For Trusts with significant numbers of responses the results were mixed, with patients having both good and bad waiting experiences (see lack of consistency). Where clinics were praised there was a prevalence of small clinics, sometimes local clinics in the community, critically where patients were given individual appointment times, rather than the ‘usual’, everyone arriving at the same time in the morning or afternoon.

**‘Every time I have been to the eye unit they are always running behind, for various reasons. They never explain things to you, doctors are unwilling to sit and discuss my condition due to having to rush through due to being behind. The waiting area is always very, very busy.’**

**‘Up until about 18 months ago I would always expect to be in the clinic for at least two hours, and it was regularly more than that. However, things started to change, and it became usual to only be there for one hour or even less.’**

**‘Over the past year, I have noticed a considerable difference in the treatment that I receive for Glaucoma and macular degeneration. Before the queues were incredibly long with 40 or so patients waiting at any one time. Now the appointments are scheduled at a more precise time so that there are only half a dozen or so patients in the system waiting to be treated or measured.’**

11. **Environment at appointment:** A significant number of patients mentioned environmental issues with appointments. These revolve around seating, or the lack of it, overcrowding, poor / inadequate signage and inappropriate visual prompts or message boards. Again, good practice was remarked on as open, clean, bright waiting rooms; with plenty of space for moving around either with a cane, a dog, a guide or a wheelchair.

**‘The department is overcrowded, the corridor long and they never ever offer assistance to get to the end of the department where you sit for hours sometimes hoping you will be next to be seen but never ever are. Dreadful awful place...’**

**‘Car parking is a joke. You have to be with someone due to the drops, but they can’t be with you as they can’t park. Ended up sitting in my own in the dept with my husband sat in the car in a queue waiting.’**

## 5.2 Deterioration due to delays

12. A number of patients expressed real concern over the effect delays in appointments were having on both their clinical condition and mental health. There was concern amongst patients that they might prematurely lose their sight due to appointment delays. This concern is borne out by the recent HSIB investigation which identified the lack of timely monitoring of patients with glaucoma as a patient safety risk priority.<sup>8</sup>
13. The HSIB report found that there was significant potential for premature sight loss amongst glaucoma patients waiting for follow ups. It also noted that loss of vision can significantly affect a person’s mental and physical health. For example, it can cause depression and lead to falls with resulting injuries such as hip and knee fractures.

'I was diagnosed with normal tension glaucoma at the relatively young age of 41. It was a scary time as I already had some visual field loss that I was unaware of. During the first couple of years since diagnosis I was terrified of losing further vision, and this was made worse by the fact that although my appointments were meant to be every 6 months, they were often up to a year apart.'

'I have been chasing an appointment due to being very overdue a check-up. I'm advised Every time to come back in 6 months. But the length of time is getting longer and longer. I have just spoken to them and they have confirmed that I was missed off the list for follow up appointments. All the staff ... are very hard working and clearly very over stretched..'

'When I am told I require treatment in 6 or 7 weeks, this is when it will be beneficial and the best for me. Over the past 18 months this has not been so. This worries me, knowing the risk of losing my sight because of delays.'

### 5.3 Continuity and consistency of care

14. **Continuity of care:** Continuity of care was mentioned on a number of occasions – this encompasses seeing the same consultant/doctor each time to build relationships, and problems experienced when having to move between Trusts or clinics within trusts. Mention was made of patient notes not being available or read and having to repeat oneself at each appointment.

'I think staff in eye outpatients should have read my notes and know I can't drive because of my eye condition. Having to repeat this information over and over again is demoralising.'

'I use hearing aids and though I put this on all the forms I filled, no one read it'

'I think that there needs to be continuity of care for patients at risk of losing their eyesight.'



**‘Currently, I see the same consultant for my glaucoma and this gives me a lot of reassurance. Continuity of care is very important to me and it helps to see a consultant who knows me - it adds a personal touch. I do worry about the future though and whether I will continue to see one consultant consistently going forward.’**

15. **Consistency of care:** Lack of consistency was mentioned in several ways. The key one was linked to appointments – either the inconsistency of timing between clinics, but very specifically in relation to cataract operations. Where patients were due to have both cataracts operated on some had both done together or within a couple of weeks, but more often the first cataract was operated on and then patients had an ‘excessive’ wait for the second operation. Patients described how this affected their lives negatively.

**‘My first operation was so stress free and I left feeling that this was a great operation. As I was so nervous the surgeon made me feel comfortable and talked me through the whole operation. However, my second operation was so traumatic and stressful if I had this on first, I would have NEVER gone back.’**

**‘The day unit was welcoming, and the staff were very good. I was understandably nervous about the surgery, but the staff made me feel at ease. The whole procedure was so quick, and far less scary than I thought it would be. From checking in at 12.30, I was home by 3.30 that same afternoon. The aftercare was excellent with the notes I was given being very comprehensive. I was called by the aftercare team a few weeks later and was told then that I would now be scheduled for the 2nd operation.’**

**Unfortunately, I am still waiting for that operation (some 3 months later) and I am told that I will not be called until May next year. That will be 9 months after the 1st operation. That is a very long time to be left with one eye corrected from a prescription of -7.75 to -0.5 and the other eye left with a prescription of -7.75. Up until having to wait so long between operations, I was very happy with the experience. This delay has somewhat soured that.’**

16. **Variability:** Overall, there is evidence of variation in service standards not just between different services across the country, but also within providers. Where several responses were received from one provider, there are both positive and negative experiences detailed. This highlights that no hospital eye service across the country is uniformly providing an exceptional service 100% of the time. Trusts should therefore not assume that their service is always great, and should be constantly looking for ways to improve.

‘.....the quality of the medical treatment has been excellent, but the delivery of the service has been absolutely appalling’

‘According to the lady I saw, there were no other options available on the NHS other than steroids which she didn’t think I was ready for. I came out feeling frustrated and upset feeling there was no hope.....  
Thankfully, I remembered meeting a specialist in inflammatory eye conditions ..... I was able to attend her clinic..... What a huge relief.  
Whilst I appreciate there is no cure for my condition, the consultant I saw appeared to really care and she was able to set out other treatment options should they prove necessary in the future, for example, surgical intervention and using eye drops prepared from blood. I feel blessed to have been able to see a specialist in my eye condition who gave me hope for the future.’

## 5.4 Staff attitudes, empathy and understanding

17. **Attitude:** The attitude of staff (at all levels) is critical to patients having a positive experience of care. Patients highlighted poor staff attitude, and how it makes them feel. On balance consultants/doctors were criticised slightly more than other members of staff. Lack of support and information were also mentioned. However, there was also acknowledgement of the difficult circumstances staff are often operating under.

‘It would be good to occasionally remind the nursing staff at the clinic that although they are on a very busy ‘production line’ always to project a calm and pleasant ‘bedside manner’. Happy but brusque is less than ideal.’

'He just kept talking over me, I wanted to know if it was the wet kind or dry, and he just kept telling me it was AMD he gave me no information, didn't answer any of my questions, and left me feeling very frustrated and a bit angry. I felt I was being treated like a stupid woman, and all I wanted was to know what to expect.'

'The response [I received] was that of someone who had heard the story once too often, not trained to do what must now be a common skill for an NHS secretary - to deal with the disappointment and frustration of patients in my situation with empathy and without trying to make them feel selfish for not simply putting up with the total financial and emotional turmoil that the hospital's last-minute decision had thrown me into. If the tables had been turned and I had simply said "I'm too busy" I'd probably have been fined.'

18. **Empathy:** Patients' stories highlighted concerns about a lack of empathy from staff for their conditions and its impact on their health, life, abilities and wellbeing. Several referred to their sight impairment and blindness as not just a medical condition – it has far reaching effects. A number felt that delivery of 'bad news' was not handled well. Patients also mentioned when they had experienced good, caring or helpful staff and the difference it made.

'I asked what the condition was. I was informed it was AMD and she also said. 'It's the worst one'. No warning, no explanation.. nothing ..I think I cried for three days.'

'Initially the staff in theatre were not welcoming and did not explain what they were going to do. The only person who explained and said what they were going to do, and the reason for it, was the person in anaesthesia. The others continued to talk to each other about nights out and holidays. I was not happy to be treated like I didn't feel or think anything.'

'....this ophthalmologist was brilliant she was very helpful and professional and took the time to listen to my eye problems which I feel is very important, also the appointment I feel was not rushed.'

‘...this ophthalmologist was brilliant she was very helpful and professional and took the time to listen to my eye problems which I feel is very important, also the appointment I feel was not rushed.’

19. **Understanding:** Several stories speak of a lack of staff understanding of eye conditions, not just clinically but also what it means or feels like to be blind or partially sighted, and the way the sight loss came about – suddenly or over a period of time. This links closely with the desire for empathy, communication and access to information. If staff (across all levels) understood eye conditions better (and what it is like to live with them) they would understand that patients are not being awkward or difficult.

‘it was a really, really stressful period - to think that you are potentially losing sight and you could be losing more because people are refusing to do anything about it. That is an incredibly, like, helpless feeling and that’s the most let down I’ve felt.’

‘My eye has improved significantly it’s been such a relief to have the right care and procedure done. To have the consultants and nurses take the time to listen to me and ensure I had my surgery done in a timely manner was remarkable. Mr [name removed] and the team are just an absolute asset to the hospital.’

‘My vision will never be perfect, but for me it’s made a huge difference. From making out my grandchildren’s faces which used to be two pink blobs, to the things you take for granted like being able to see where the cup is when making a coffee and seeing the time on my computer – I haven’t been able to see that for 10 years. I feel like I’ve turned a corner and each day amazes me. Nearly two years ago I was relying on touch and sound, but now I’ve been able to do things by sight again. It’s made my life so much better.’

## 5.5 Communication and access to information

20. **Accessibility:** Having information in an accessible format is mentioned numerous times. There is an Accessible Information Standard enshrined in law (and outlined in the RCOphth Commissioning Standards for Ophthalmic

services<sup>15</sup>) but this does not seem to be followed or understood by all providers. The need to use large font, perhaps coloured (yellow) paper, communicate by text or e-mail similarly. Above all, Voices comment that they are either not asked and just sent things in the normal way (typically a letter in the post which they have difficulty reading, or can't read and have to ask someone else to read out to them which doesn't consider patient privacy), or they are asked (or they tell the provider what they need) but providers then cannot provide information to the requirements.

**'All the appointment communications were by manual paper letter, no digital options were offered so I couldn't select an appointment suitable for me. Digital would not only be easier but also save money for the NHS.'**

**'There is a real problem with the way in which information is communicated with patients. I am blind, yet I repeatedly receive letters, despite having asked for information to be sent to me by e-mail, which I can access and listen to on my own. I want to be the first to read my diagnosis, or what is going to happen to me, and be able to choose if and when I tell other people, my family, my wife. It is completely unacceptable that family, friends or carers are the first to know things about me, because I cannot read the information sent to me.'**

**'I think the eye clinic could improve when it comes to patient letters. I like to have a letter after each appointment which gives a clear treatment plan and says when I should expect to be seen next. This helps me to feel in control of my eye care. This isn't always consistent.'**

21. **Access to information:** A few Voices commented on issues with Trusts providing information (particularly case histories / patient notes) throughout the patient journey.

**'I have also had difficulty in obtaining a printed copy of my visual field tests. On one occasion last year I met huge resistance and had to make a Subject Access Request which took over 3 months. I believe that patients should be provided with their test results immediately as a matter of course if requested.'**

22. **General communication:** Communication in general was raised by Voices. Particularly in relation to a perceived lack of explanation or information provided in a timely manner, and/or promised contact not materialising/not happening within the promised timescales.

**‘Patients are given the time they need to be involved in patient centred clinical decision-making processes, with clear communication to GPs using Plain English and minimal acronyms and abbreviations. My GP marvels at these letters upholding them as excellent examples of hospital to GP communication.’**

## 5.6 Support for patients (including ECLOs)

23. Where Eye Care Liaison Officers (ECLOs) were mentioned they were universally acclaimed. Whilst most patients referred to the value of ECLO’s to themselves one or two did reference the value to the provider themselves – freeing up other (clinical/admin) staff to concentrate on ensuring effective handling of patients.

**‘I find the Eye Clinic Liaison Officer (ECLO) service at the hospital to be very helpful. The ECLO is a place to turn when you’re unsure of who to ask and I always find that once I’ve spoke to the ECLO that the issue gets resolved. The ECLO is of great support to me.’**

**‘I think it is really important that consultants have some sort of checklist about support services, within or even out of the hospital. Something like an ECLO or an LVA [Low Vision Assessment] or a rehab officer or access to work, you know, whatever it may be, they can go and tell the patient are you aware of this, did you know that? Then the patient can go away and look it up in more detail. I know consultants don’t really have the time to go through all of that, but as long as they have told that information. Because half of the time patients are unaware of anything that is out there that is available to them and they just live in isolation.’**

## 5.7 Transport and access

24. Several patients commented on the location of clinics and other services and the facilities provided – this was often in relation to transport difficulties and/or disability access. On the positive side a couple of patients mentioned the provision of a mobile clinic in a convenient local location (e.g. supermarket car park) – which was very well received.

**'I then had regular 4 weekly visits to their mobile macular unit at Tesco's in Camberley. Very slick operation.'**

**'The diabetic eye screening has been outsourced and localised, but most of the locations aren't on bus routes. Because I'm a wheelchair user and blind I can't drive and need to use buses and have someone to help me use them; this means I've not been able to get to the locations. Eventually a central location was offered and when I checked that the tests could be done from my wheelchair, I was told they no longer have any facilities for people who can't transfer to a seat and manoeuvre their body to the equipment. I was told I should be referred to the hospital eye dept, but they said they don't do first line diabetic eye screening. I'm caught in a loop with no screening available.'**

**'The clinics are run as one stop clinics so that all testing takes place prior to the final consultation with the Dr so that all information is up to date and informing treatment options. The clinic letters inform what the expectation of attendance at the clinic will entail including time frames and not driving. I have recently required surgery and the whole process has been managed really efficiently and quickly including communications from the administrative team. The whole team provide a level of service that instils confidence in the treatment being received.'**

**'I had two cataract operations within 10 weeks of each other. I was treated quickly and efficiently on each occasion. The procedures took place in a mobile department in the car park of the hospital in order to treat the back log of patients who were awaiting this treatment. It was all very successful.'**

# 6. Recommendations

1. Whilst the findings from 100 Voices show that there is good practice to be celebrated, there is significant variability in experience of eye services and many areas for improvement. A number of recommendations are made below, based on the findings of this report. In formulating its recommendations, this report draws on a number of other publications including the recent HSIB<sup>8</sup> and GIRFT<sup>9</sup> reports and NHS RightCare toolkit.<sup>10</sup> Where other work has been drawn upon in formulating a recommendation, this is noted and referenced as appropriate.

## 6.1 Personalising care and supporting self-management

2. Personalised care means people have choice and control over the way their care is planned and delivered. It should be based on what matters to them and their individual strengths and needs. Patients should also be supported to self-manage their condition (as appropriate) as the evidence shows that those who do so (and have the skills and confidence to do so) experience better health outcomes.<sup>10</sup>
1. **Recommendation 1: Local health systems (both commissioners and providers of eye-care services) should make use of the Patient Journey Map created as part of the 100 Voices Project to assist in engagement, developing thinking and service improvement.**<sup>12</sup>
2. **Recommendation 2: Providers of eye-care services should explore ways to make it easier for patients to make and communicate regarding appointments.** For example, allowing patients to make appointments at appropriate times; making it easy to change appointments. This is likely to reduce DNA's and increase the efficiency of clinics and patient throughput.
3. **Recommendation 3: Providers of Hospital Eye Services should comply with and fully implement NICE Quality Standard 180.**<sup>16</sup> NICE Quality Standard 180 notes that individuals with serious eye disorders should be given the opportunity to discuss their diagnosis, prognosis and management, and



should be provided with relevant and accessible information and advice at clinic visits in accordance with NICE guidance. The use of appropriate patient decision aids may also be helpful in terms of ensuring patients have access to the right information to inform decisions about their care.

4. **Recommendation 4: Providers of eye-care service should make use of patient activation tools to support patients in self-managing their condition.** There is a growing body of evidence that highlights the importance of effective self-management of long-term conditions, including eye conditions such as glaucoma. Those who recognise that they have a key role in self-managing their condition, along with the skills and confidence to do so, experience better health outcomes. Yet the ability of people to successfully self-manage and stay well at home can vary considerably from person to person. Developing the ability of, and supporting individuals to, self-manage their condition is a key part of the Long-Term Plan.<sup>1</sup> Patients can be supported to self-manage through the use of patient activation tools (and measures) and it is recommended that services should incorporate these tools into the patient pathway.<sup>17</sup>
5. **Recommendation 5: Providers of eye-care services and those supporting patients with eye conditions should provide appropriate training, education and support tailored to a patient's activation level. This should particularly target support and interventions at people with lower activation levels and disadvantaged groups to address health inequalities and support them to self-manage.** Providers of eye-care services should ensure that the training, education resources and support they provide is tailored to the activation level of a patient. Education on how to use eye drop medication and what action to take if care is delayed, or new symptoms occur, are key. Available resources and support should particularly be targeted at those with lower levels of activation and who are less confident in their ability to manage their own care. This can support patients to gain in confidence and increase their activation levels. As well as targeting resources at those with lower activation levels, services should develop and target interventions at disadvantaged groups in order to increase their health literacy and patient activation.<sup>17</sup>
6. **Recommendation 6: Providers of eye-care and support services (including charities, third sector organisations and carers) should**

**provide outreach and education to ensure that they support people to prevent potential future sight loss.**

## 6.2 Improving services and experience

7. Evidence suggests that when patients and service users have ‘good’ experiences of receiving care, they are more likely to become better engaged with their own healthcare. This can lead to improved patient/service user outcomes and productivity gains for NHS services.<sup>10</sup>
8. **Recommendation 7: NHSE&I and local health systems (both commissioners and providers of eye-care services) should improve local understanding of the patient experience of eye-care services through the regular collection of patient feedback. This should be used to improve and develop services.**<sup>10</sup> Both commissioners and providers of eye-care services should ensure that they have a good understanding of the patient experience of local eye-care pathways and services. Services should collect experience of care feedback from patients and carers on an ongoing basis (for example through capturing and analysing complaints and compliments). This should also include capturing patient stories to identify what is working well (and do more of it) and what could be improved. Make use of patient’s stories at public board/governing body meetings and remember to celebrate success as well as looking at what can be improved.<sup>18</sup> Services must also ensure that improvement activities and changes are actively communicated to patients and service users. One of the biggest complaints from the Voices captured in this report was that their stories were never acted on (or at least that is how it seemed to the individuals concerned). The collection of patient feedback and patient stories should also be embedded within local service specifications and contracts.
9. **Recommendation 8: All providers of eye-care services should ensure full compliance with the Accessible Information Standard.**<sup>19</sup> The 2016 Accessible Information Standard places a legal duty on all providers of NHS care (and publicly funded adult social care) to ensure that people with a disability or sensory loss are given information they can understand, and the communication support they need. The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users,

carers and parents with a disability, impairment or sensory loss. This should include ensuring that signage and information at eye-care clinics is fully accessible; and that patients are given the choice of receiving appointment details/reminders and clinic/care information in large print or electronically via email or text where preferred. Where guidelines and mandates already exist, providers must take steps to check compliance on a regular basis as there is clear evidence that the standard is often not adhered to.

10. **Recommendation 9: All providers of eye-care services should take steps to ensure that their services (including staff, communications and clinic space) are accessible to those with learning disabilities.** Further to recommendation 7 above, all providers of eye-care services should take steps to ensure that their services are accessible to those with learning disabilities. This should include ensuring that all services have alternative provision in place to assess Visual Acuity (including Kay Pictures, Cardiff Cards and Bradford Visual Function Box in addition to Snellen and LogMar charts). Providers should also be aware that many individuals with learning disabilities will be unable to manage visual acuity tests, and therefore their vision may need to be assessed on a functional basis. Services should also ensure that they implement NHS mandatory training for staff around the needs of people with learning disabilities; and take steps to build links (and work) with other learning disability support staff within their organisations. Services should make use of the support resources developed by SeeAbility; and signpost these to appropriate patients, their families and carers.<sup>20</sup>
11. **Recommendation 10: Providers of Hospital Eye Services should comply with and implement NICE Guideline 81: for the diagnosis and management of Glaucoma.**<sup>21</sup> In its investigation, the HSIB identified that despite NICE issuing guidance on standards for following up patients with glaucoma, these were not being adhered to.<sup>8</sup> The findings of this report confirm that patients often feel that they have to wait longer than recommended for their follow/check-ups and that this is putting their sight at risk. Providers of Hospital Eye Services for patients with glaucoma should fully implement and comply with NICE Guideline 81 within their services.
12. **Recommendation 11: Providers of Hospital Eye Services should implement failsafe prioritisation processes to address appointment**

**delays and report on performance against these.** Providers should develop and implement failsafe prioritisation policies and processes for following up with patients, in line with the NHSE&I High Impact Interventions in order to manage risk of harm due to appointment delays to ophthalmology patients. NHSE&I have been working closely with colleagues from NHS Digital and the RCOphth to enable national reporting against this follow-up performance standard. There is now quarterly reporting of this data with the expectation that reporting will become mandatory from April 2021.<sup>22</sup>

13. **Recommendation 12: NHS Digital and NHSE&I should work to include provision for identifying, prioritising and monitoring patients at risk of developing sight loss within the national Commissioning Data Set.** The HSIB report<sup>8</sup> recommends that NHS Digital should include provision for identifying, prioritising and monitoring patients at risk of developing sight loss within the next version of the national Commissioning Data Set. It recommends that provision should include the ability to record a risk rating and the recommended follow-up date for each patient, as mandated data items for collection by hospital eye services. This should be carried out in consultation with key stakeholders, including RCOphth and patient administration system suppliers.
  
14. **Recommendation 13: Local health systems (both providers and commissioners of eye-care services) should consider eye services from the patient perspective, ensure that the patient voice is properly represented on local eye health groups, and involve visually impaired people in the design/redesign of eye-care service facilities.** Further to recommendation 7 above, providers of eye-care services should ensure that they have adequate patient representation in all groups considering the design, development and performance of eye-care services.<sup>10</sup> This should include ensuring that they review their services through the lens of the patient. People with a visual impairment (including those with other disabilities and complex needs) should always be involved in the design and redesign of all facilities where eye-care services are (or may be) provided; including signage, layout of clinic space, guidance/information provided in clinics and equipment (to ensure it is accessible to those with complex needs). All design and redesign should focus on patient need and practicality, not what is aesthetically pleasing to people with 'normal' vision. Most of the people engaged with as part of this work indicated a willingness

to be involved in future service development – they just need to be asked. Captured feedback should also be used to inform the redesign of facilities. For example, Manchester Royal Eye Hospital (MREH) has successfully engaged patients to support the redesign of information and signage within clinics and the sharing of information about conditions. This has included exploring digital options for providing and sharing information.<sup>26</sup>

15. **Recommendation 14: Local health systems (both commissioners and providers of eye-care services) should consider alternative models of delivering services.** Local health systems should explore how to better manage appointments to improve patient flow, reduce waiting times (both before and during appointments), reduce DNA's and improve patient and staff experience. Consider Journey Mapping and Value Stream Mapping of existing services and introducing community based/mobile services. GIRFT recommends that this should include reviewing pathways to identify whether any are creating demands on space that could be met in different ways.<sup>9</sup> For example, MREH have implemented community treatment centres for the delivery of macular injections in order to reduce wait times and improve the patient experience (and waits) at clinics.<sup>26</sup>
16. **Recommendation 15: NHSE&I should continue to prioritise the development, redesign and transformation of ophthalmology services.** Much good work has been achieved through the ECTP programme. It is recommended that this improvement work should continue. It is understood that ophthalmology will continue to be a priority for the National Outpatient Transformation Programme. The programme will be working closely with key stakeholders (including clinical leaders and other national delivery partners) to undertake clinically-led pathway redesign for ophthalmology and ensure that those patients most in need are seen in the right place, within clinically safe time frames.

## 6.3 Developing staff

17. Workforce capacity is a key problem and there needs to be an optimisation of the skills and expertise available across local systems, with multidisciplinary working across primary, community and secondary care sites. Non-clinical support staff play a vital role not only in ensuring that clinicians time is not taken up performing administrative duties, but also to provide emotional and

practical support to patients who have been given a diagnosis of a chronic or sight threatening/loss condition.<sup>10</sup>

18. **Recommendation 16: All providers of eye-care services should take steps to fully implement ECLOs within their services.** There is significant consensus that ECLOs are an invaluable resource for patients and should be available at all providers. All hospital eye services should have an ECLO, compliant with RNIB standards<sup>23</sup>, as part of the eye service team in order to undertake non-clinical functions; and to advise, support and advocate for patients. The provision of ECLOs is also important for relieving pressure on clinical staff as they provide the wider support needed by service users, which, without an ECLO, falls on those staff or doesn't happen at all.

**“I work as an Eye Clinic Liaison Officer (ECLO) and offer practical and emotional support to anyone affected by sight loss. ECLOs are a point of information, support and onward referrals to support within the community. Many patients have remarked that it's very helpful to have a place where they talk to someone, ask questions and digest the news. We would love every eye clinic in the UK to have an ECLO service to ensure the support is available to all and no-one misses out, after all, sight loss is not a challenge to face on your own.”**

19. **Recommendation 17: Providers of eye-care services should look to upskill existing staff where appropriate.** Services should explore opportunities to upskill staff and consider alternative workforce models to address capacity issues. For example, developing optometrists with independent clinical and prescribing abilities to reduce dependence upon consultants (Advanced Clinical Practice). 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.<sup>8</sup> In developing staff, providers should utilise the Ophthalmology Common Clinical Competency Framework (OCCCF),<sup>24</sup> which sets out agreed standards of knowledge and skills for a variety of roles for all non-medical ophthalmic professionals working in hospital eye services.

**‘I wish there were more Optometrists with Independent Prescribing to fill the gap between the techs and the consultant, like me. We could take a lot of the work so the consultants could concentrate on surgery.’**



20. **Recommendation 18: Sight awareness training should be mandatory for staff involved in the provision or commissioning of eye-care services. Providers of eye-care and support services should therefore take steps to provide this for their staff; working with the third sector (RNIB and others).** All staff involved in the commissioning, administration and delivery of eye-care services should undertake sight awareness training to gain a greater understanding of the experience of individuals living with visual impairment and sight limiting conditions. This should include experiencing different eye conditions, guiding training and 'blind walks' (where possible). All organisations involved in the provision and commissioning of eye-care services should note that there is a need to improve staff attitudes, empathy and understanding in some areas. Organisations should not be complacent on this front. This should also include ensuring that staff are aware of the patients attending each clinic and their individual needs (perhaps through a team briefing at the start of each clinic and/or ensuring that relevant staff read a patient's notes first) so that continuity of, and appropriate, care can be provided. This can help ensure that patients have a good experience of care. Providers should ensure that they make efficient and effective use of administrative staff in order to optimise the productivity of clinical staff.<sup>10</sup>

## 6.4 Navigating services

21. The complexity of how ophthalmology services are delivered can make it overwhelming for patients to successfully navigate services. Patients need simple consistent pathways and clear information on how and where to access different services (for example social services, sight loss rehabilitation services, third sector support).<sup>10</sup>
22. **Recommendation 19: Local health systems (both commissioners and providers of eye-care services) should ensure that ophthalmic pathways of care are simple, easy to understand and consistent across the system and are communicated clearly to staff, primary care providers and patients.**<sup>10</sup> Ensure that all parts of the system work together to remove barriers and hurdles. This is especially important across commissioning and provider boundaries, and at key times for patients such as transition from child to adult services.

23. **Recommendation 20: Providers of eye-care services and other organisations providing support to those with eye conditions (including charities and third sector organisations) should ensure that consistent information on available services is signposted.** ECLOs, and all other staff involved in the delivery of eye-care services and support for those with eye conditions (who have contact with patients and carers), should have all relevant information to be able to effectively support and signpost patients to relevant services across the system (including social services, sight loss rehabilitation services, third sector support services). This could be through the development of a Directory of Service. They should take steps (including via contractual means where appropriate) to ensure that mechanisms for referral into these services are straightforward and that services can be accessed in a timely manner
24. **Recommendation 21: Providers of Hospital Eye Services should work with their commissioners and community services (as appropriate) to implement appropriate referral and triage systems for referrals into secondary care to reduce waiting times.** Best practice, as outlined by the NHSE&I Ophthalmology Elective Care Handbook,<sup>25</sup> suggests that implementing appropriate triage systems for referrals into secondary care (for example for glaucoma), can significantly reduce waiting times (at least for new appointments), and improve capacity issues. Commissioners and providers should therefore work together to implement effective local triage processes. The HSIB notes that capacity can be maximised by ensuring referrals to, and follow-ups by, hospital eye services are appropriate and by introducing new ways of working.<sup>8</sup>



# 7. Acknowledgments

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  5. NHS Hospital Eye Services
  6. NHS RightCare
  7. NHS South, Central and West (SCW)
  8. Patient Experience Network (PEN)
  9. Royal College of Ophthalmologists (RCOphth)
  10. Royal National Institute for Blind People (RNIB)
  11. SeeAbility

For more information please contact: [nhsi.outpatient-transformation@nhs.net](mailto:nhsi.outpatient-transformation@nhs.net)

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