#### healthwetch

# A strain on sight: Waiting for NHS specialist eye care

# Key findings and summary recommendations

- Eye care is the busiest outpatient speciality in the NHS in England. With an ageing population, demand is set to grow further. While eye care can transform the lives of those who receive it, often helping to prevent sight loss, new Healthwatch England research shows a concerning picture about the experience of waiting for care.
- Getting referred for specialist eye care can be challenging. Our survey of those currently waiting shows that almost a quarter (22%) had to have multiple appointments before being referred. As we uncovered in <u>previous work</u> on hidden waiting lists, there is a risk that those who need multiple appointments will have delayed treatment.
- Even once referred, many people experience long waiting times for specialist eye care. According to official statistics, for those currently waiting as of December 2024, only two thirds have been waiting

less than the 18-week target set by Government, compared to a target of 92%.

- Of those currently waiting who completed our self-selecting survey, nearly two thirds (64%) had been waiting more than four months for care, while nearly one in four (24%) have waited over a year.
- Most people in our survey said their vision got worse while they waited. Of those currently waiting for treatment, 70% said they have noticed some deterioration in vision, compared to 53% of those who had received eye care treatment in the last two years.
- Waiting for eye treatment significantly impacts people's lives. Over half of those currently waiting said the wait had affected their ability to work (54%) and carry out daily household tasks (52%). Seven in ten (69%) said it had affected their mental health and three quarters (75%) said it affected their ability to continue with hobbies. This report includes the personal stories of some of the patients affected.
- Very few people had support while they waited or were kept up to date by services. Just 4% said they had been given information and advice to help with day-to-day activities like working, while less than one in ten (9%) said the NHS kept them up to date about

their waiting time for treatment. Healthwatch England continues to press for better support for patients who are waiting for treatment.

- Many people are unable or unwilling to access private care to avoid waiting. Over a third (34%) said they could not afford private treatment. Although some people who previously had to wait did access private care, some had to borrow money to do this. Others were able to access NHS support via a private provider.
- There is strong public support for optometrists to play a more significant role in helping those needing specialist eye care. The vast majority (85%) of people support the idea of optometrists being able to refer patients without them having to see a GP, and over 65% are comfortable with opticians helping to monitor and treat eye conditions.

#### Summary recommendations

### The NHS should publish ophthalmology waiting list data by condition.

- The NHS currently publishes waiting list data for all ophthalmology treatments together.
- Condition-specific data would allow increased scrutiny of waiting time progress for the most serious conditions, and ensure resources are being appropriately allocated.

## The Government should make greater use of optometrists to help cut waiting times and provide more treatment and aftercare closer to home.

- Optometrists in the community are highly skilled and in every locality in England.
- Respondents to our survey supported making better use of their skills, which could improve patient experience.

### Improved support and communication for patients while they wait

 Eye Care Liaison Officers, (ECLOs) provide vital support to those diagnosed with a condition that affects their sight.

4 A strain on sight: Waiting for NHS specialist eye care

- In England, the current ECLO coverage in the top 150 ophthalmic centres is 71%.
- The NHS should ensure trusts and other commissioners and funders of eye care services support the increase and sustainability of the funding of this programme alongside RNIB, with universal access as the ultimate aim.

#### Introduction

NHS eye care services are delivered both in the community at local opticians and within secondary settings, by the NHS or private contractors. Together, these services are essential for diagnosing, treating, and preventing disorders that, if not addressed, can have a devastating effect on people's lives.

As of December 2024, <u>nearly 600,000 people were</u> waiting in England for secondary eye care treatment, one of the largest waiting lists in the NHS.

The NHS doesn't break down ophthalmology statistics by individual condition. We therefore don't know how many people are waiting for treatment for reversible conditions such as cataracts, as opposed to irreversible conditions such as glaucoma, where failure to get timely treatment can result in permanent sight loss.

Following feedback from the public about long waits for ophthalmology services, we looked more closely at the issue.

This report examines the results from our survey of over 1,000 people's experiences of currently or recently

waiting for specialist eye care from August to September 2024.

We asked about people's experiences while waiting for treatment or referral, including the options offered and the support received.

We recognise that professionals across the eye care sector are working tirelessly to address the challenges people face accessing specialist eye care, including by providing better support to patients while they wait. The <a href="Eye Care Support Pathway">Eye Care Support Pathway</a> is one example of this.

By shining a light on people's experiences, we hope to provide direction on how the NHS and other services could improve how people access, wait for and receive the specialist eye care treatment they need.

#### What we did

Healthwatch England ran an online survey from July to September 2024. The survey was shared by us on social media, as well as by supportive partners. These included eye care charities, members of parliament and professional organisations, and the Healthwatch network in their local communities.

The survey was self-selecting, meaning that we relied on those people who were willing to complete the questions and had the ability to complete an online survey.

In addition, ten Healthwatch were commissioned to gather responses in their communities, focusing on the experiences of people from ethnic minority groups:

- Healthwatch Bury
- Healthwatch Cambridgeshire and Healthwatch Peterborough
- Healthwatch Croydon
- Healthwatch Doncaster
- Healthwatch Ealing and Healthwatch Hammersmith and Fulham
- · Healthwatch Lambeth

- Healthwatch Leicester and Healthwatch Leicestershire
- Healthwatch Sandwell
- Healthwatch Westminster

#### Who we spoke to

In total, we heard from 2,568 people about their eye care experiences:

- 1,766 people responded to the questions about having eye tests in the last two years.
- 471 people responded to the questions about currently waiting for secondary eye care.
- 580 people answered the questions about secondary eye care in the last two years.

This report focuses on the 1,051 people who responded to the questions about waiting for secondary eye care. We use the statistics from the survey and responses to free text questions to illustrate the impact on people of waiting for eye care.

We will publish a second report detailing the experiences of the 1,766 people who told us about their experiences of eye tests and primary eye care.

# What conditions people needed specialist care for

We collected data about the conditions people were seeking treatment for. The most common conditions people told us about were:

- Cataracts (33% of those waiting for treatment and 13% of those who had had treatment in the last two years)
- Glaucoma (12% of those waiting for treatment and 9% of those who had had treatment in the last two years)

Other conditions people needed help with were:

- · Diabetic retinopathy
- Macular holes/degeneration/oedema
- Laser treatment
- Uveitis
- Detached retina

Blocked tear ducts				
Some respondents had multiple conditions.				

# People can find it difficult to get referred for specialist eye care

Previous Healthwatch England research has <u>explored</u> the hidden waiting lists for treatment referrals from general practice (for specialist healthcare treatment in general).

Our new research on eye care referrals found that over two in five (44%) currently waiting and almost half (48%) of those who waited in the last two years were referred for specialist care after their first appointment with a GP.

However, many people required multiple appointments before being referred: one in five (22%) of those currently waiting, and over one in seven (15%) of those who previously waited. As we uncovered in previous work on hidden waiting times, there is a risk that those requiring multiple appointments will have delayed treatment.

Waiting time for referral	Currently waiting for NHS specialist eye care treatment	Received specialist eye care treatment in the last two years (NHS or private)
Referred the first time they saw a health professional	44%	48%
Optician told them to speak to GP who immediately made a referral	16%	13%
Had multiple appointments before being referred	22%	15%
Other	17%	23%

# People can wait a long time for specialist eye care treatment

Statistics from the NHS of those who have completed treatment in December 2024 show that the average waiting time for outpatient ophthalmology was around 8 weeks with nearly all patients having waited less than a year. The average waiting times for inpatient treatment were slightly shorter.

For those currently waiting as of December, however, only two thirds have been waiting less than the 18-week target set by Government, compared to a target of 92%.

NHS stats are not segmented by specific eye care condition, so we don't know the differential waiting times between reversible and irreversible conditions.

In our self-selecting survey, we asked respondents how long they had been waiting or had waited for specialist eye care. Their responses indicated a range of waiting times, from less than one month to more than a year. Note that as our survey was self-selecting, these results are not representative of average waiting times (which are set out in NHS statistics).

Nearly two thirds (64%) of respondents who were currently waiting for eye care had waited four months or more at the time they responded to our survey. This compares to 38% of those who had received specialist care in the last two years.

Nearly a quarter (24%) of those who were currently waiting had been waiting more than a year. This compares to 14% of those who had received eye care in the last two years.

Waiting time	Currently waiting for NHS specialist eye care treatment	Received specialist eye care treatment in the last two years (NHS or private)
Less than a month	16%	30%
1 - 3 months	20%	32%
4 - 6 months	21%	15%

Waiting time	Currently waiting for NHS specialist eye care treatment	Received specialist eye care treatment in the last two years (NHS or private)
7 - 12 months	19%	9%
More than a year	24%	14%

The results show that eye care services, like other specialist services, can have long waiting lists of more than a year in the worst cases. Below we set out the experiences of those who have to wait for care.

### The impact of waiting

Long waits significantly impact people's quality of life. We asked people who were currently waiting and those who had received eye care treatment in the last two years a series of questions about how the wait for treatment had impacted their day-to-day life.

Area of life impact	% negative impact: currently waiting	% negative impact: had treatment in past two years
Continue with hobbies	75%	63%
Mental health and wellbeing	69%	55%
Work (paid or voluntary)	54%	42%
Carry out household tasks	52%	41%
Socialise	48%	39%
Live independently	43%	34%

Exercise	41%	35%
Relationships	36%	29%
Care for others	32%	29%

Of those currently waiting, 70% said they noticed some deterioration in vision. This was significantly more than the 53% of those who waited in the last two years.

"My father should have six-weekly injections for macular degeneration. His appointment before last was 21 weeks. His eyesight deteriorated greatly and his optician referred him as an urgent case. We didn't hear anything and despite constant phone calls to the hospital, no one returned our calls. Eventually we complained to PALS who managed to arrange an appointment two weeks later. His eyesight is now so bad he cannot read [or] use any form of screen and [this] has had a negative impact on his wellbeing."

The summary table above shows similar concerns across those waiting and who had previously waited, with the top four areas affected being hobbies, mental health, work, and household tasks.

Over half of those currently waiting said that worsening vision while waiting for treatment had affected their ability to work (54%) and carry out daily household tasks (52%).

"My optician is great, the hospital service was poor and the wait for Laser ridiculous. It's been over six months and I've had a reoccurrence of the bleed. I'm unable to drive and consequently unable to work."

A significant majority (69%) of those currently waiting said waiting for eye care had had an impact on their mental health and on their ability to continue with hobbies, like watching TV (75%).

"I was anxious about the wait and wondering how long I would have to wait. It did not help my mental health."

"I used to love reading books and going out but can't read anymore and rarely go out as impacts on my self confidence."

Nearly half of people currently waiting (43%) said poor sight was affecting their ability to live independently.

"I need carer support as I still can't see well after treatment. I can't see steps etc. or read, or do my hobbies."

Some of the qualitative responses highlight where things have been working well. People described staff that explained treatment and identified other ways of helping them with their sight problems:

"I have been on the waiting list to see a specialist for 18 months for my cataract. Six weeks ago I saw the consultant and he confirmed I will have surgery within six weeks. When I was 27 I was punched in the right eye at a concert. I have been partially blind since then. In my appointment the consultant suggested I could have cornea replacement surgery and booked me in to see another consultant at the same hospital in two months' time to explore if I can have this surgery as this would be life changing. The eye clinic at [the local] hospital have gone above and beyond. The care has been so thoughtful."

"I have found the eye clinic and staff to be the very best. It was organised online by direct referral from [the opticians]. As the clinic is part of a GP practice, not my own, the waiting list is shorter than the hospital as there aren't the emergencies. All staff are kind and thoughtful.

I also feel safer in there from an infection point of view. An absolute fantastic service and I'm almost looking forward to my second eye being dealt with."

People also appreciated support from opticians who were able to make direct referrals:

"My optician was brilliant after waiting so long or getting up-to-date information from the NHS eye clinic my optician referred me directly to a private clinic. As I consider my optician (professional) knows my eye health best, I think this is fantastic to be able to refer me directly for cataract surgery. Thank goodness I didn't have to go completely blind before I got seen to."

#### Limited support while waiting

Our survey also asked people about the type of support they received while waiting for care.

People generally could not recall having had much support during their wait. This applied to those currently waiting for care and those who previously waited. Of those currently waiting, 67% said they couldn't remember being offered any further support, compared to 54% of those previously waiting.

The most common type of support people recalled having was 'knowing who to contact for further information', though this was selected by only 14% of those currently waiting and 26% of those who have had specialist eye care in the last two years.

Just one in 25 (4%) of those currently waiting said they had been given information and advice to help with day-to-day activities like working.

Only 9% of those currently waiting said the NHS kept them up to date about their waiting time for treatment.

These findings show how important it is to emphasise the support available to patients under various 'waiting well' schemes. This could include mental health, day-to-day living and management, and other support, which people who responded to our survey told us that they wanted but rarely received.

Communication was a key topic in the qualitative statements people shared about their care while waiting to be seen:

"I get sent texts from the hospital [...] asking if I still need the appointment and would I be happy transferring to a different consultant if that would reduce the waiting time? I've now had about four of these and I'm still waiting so my responses don't appear to be considered."

"I have had no communication at all from the hospital that I have been referred to, not even an acknowledgement that I have been referred. The NHS does have a page for the referrals I am waiting for, but this page is hard to find (it should be on the main menu). This page says the waiting time is 20 weeks and I have been waiting 8 weeks."

We also heard that people waiting for eye care experienced difficulties in understanding the letters they had been sent by the NHS, as they were not designed for people with sight problems:

"I think that the NHS should look at its letters and web pages as they are not suitable for people with eye problems. Trying to read information that is presented in 6 or 8 pt is cruel. It seems pretty obvious that clear, large lettering would make it so much easier."

From someone who has already had their care, this experience captures the many points in the journey where good communication was essential:

"After waiting 18 months for my operation it was cancelled on the day because of emergency cases. I had been prepped and ready, waiting six hours, only to be sent home. The reason was completely understandable but it caused considerable stress particularly when the operation was rescheduled but I wasn't told about it. Eventually I was able to have it done the following week for which I was grateful and thankful that it was over. The biggest issue over the 18 months was to do with appointments and having to phone to find things out myself instead of being kept informed."

# Views on going private for specialist eye care

We asked those currently waiting for care to select from a series of statements related to their willingness to access private treatment. We asked those that had previously waited to select from a slightly different set of statements about private treatment that were comparable to the questions asked of people currently waiting for care. We also provided people with an opportunity to explain their response in free text.

Currently waiting for care		Received specialist eye care in the last two years	
Attitude to seeking private care	Percentage	Attitude to seeking private care	Percentage
I'd have gone private for a shorter wait, but I	31%	I'd have gone private for a shorter wait, but	16%

can't afford it		I couldn't afford it	
I'm looking into whether I can afford private treatment because the NHS wait is too long	7%	n/a	n/a
I'm considering borrowing money to access private treatment	2%	I borrowed money to access private treatment	24%
I can afford private treatment and am arranging it	2%	I could afford private treatment and decided to get it	0%

I would only pay for private treatment in the most extreme situations	23%	I didn't access private care, but I would consider it in the future if my condition was bad enough	9%
I won't use private treatment and never would	15%	I didn't use private eye care and never would	26%
Other	20%	Other	25%

Nearly a third (31%) of those currently waiting said they could not afford private treatment, compared to 16% of those who had received eye care in the last two years. In the free text responses, people cited cost of living issues:

"I can't afford it. Many people can't and are in the position of having to prioritise keeping security of a home, warmth and food over paying for any health issues."

Of those currently waiting, 15% said they would never use private treatment. This compares to 26% of those who had had specialist treatment in the last two years.

Of those willing to pay for private treatment, the most common response was, 'I would only pay for private treatment in the most extreme circumstances' (23%). Smaller numbers of people said that they would consider private treatment, with 7% stating they were 'looking into whether I can afford private treatment because the NHS wait is too long', 2% 'considering borrowing money', and 2% that 'can afford private treatment and am arranging it'.

Of those who had received specialist eye care in the last two years, a quarter (24%) said 'I borrowed money to access private treatment'. A further 9% indicated that while they did not access private treatment last time, 'I would consider it in the future if my condition was bad enough'. Only two people said they could afford to pay for care, representing less than 1% of respondents.

Almost half of the respondents in either group (those currently waiting or those that waited in the last two years) were not considering using, or did not use, private treatment due to financial considerations. Some would never choose this option.

Of those currently waiting, it would take extreme circumstances for the majority to consider private treatment. For those that had undergone treatment in the last two years, most of those that had used private treatment borrowed money to do so.

In the free text, people explained why they had gone or were considering going private. Their reasons included long waits for NHS care and worry that their eye condition would deteriorate in the meantime:

"The wait for NHS cataract surgery was too long and my glasses needed changing every 6-8 weeks."

We also heard from people that felt using private healthcare at a stage in their treatment would lead to better outcomes for them.

"I paid because the NHS eye care treatment would have left me paying for multiple glasses for daily activities. Too basic. And would have eventually cost more than the private treatment. So I paid for laser treatment and special lenses. Very glad that I did."

There were high numbers of "other" responses to this question. In these responses we heard about affordability of private care, but also about people who

had received NHS care from a private provider under the NHS Right to Choose scheme. This was often because the waits for NHS care were very long. People who opted for this were generally very appreciative of the opportunity to get swifter treatment:

"[Second] cataract being treated by private clinic paid by [the] NHS. I was given the choice of NHS hospital ... [approximate] wait 6 months or private so decided private as it's quicker."

# Support for change and our recommendations

There was broad support for opticians to take on an expanded role in referrals and condition management.

The vast majority of those currently waiting (85%) agreed the statement 'I trust an optician to refer me directly to NHS specialist services or tests for any eye condition I might have, without having to see a GP first,' while similar numbers of those who had previously waited agreed (88%).

For the statement 'I would be comfortable going to qualified professionals working in a high street opticians for the monitoring or treatment of an eye condition,' 68% of those currently waiting agreed, with 70% of those who had previously waited agreeing.

In <u>our work on Pharmacy First</u>, there was broad support for expanding the range of conditions that could be addressed at pharmacies rather than just GPs. The results in this survey also suggest support for expanding the role opticians and optometrists could play in referring eye conditions and maintaining them following further consultation.

### The NHS should publish ophthalmology waiting list data by condition.

Our data reveals a worrying picture about the extent and impact of deteriorating conditions while people wait for ophthalmic treatment. However, we don't have enough data from the NHS to break down waiting lists in more detail than across all ophthalmic conditions.

We also know from a <u>recent survey</u> of ophthalmology clinical leads that there are specific concerns from clinicians about their ability to meet the needs of glaucoma patients.

Better, more granular data would allow increased scrutiny of waiting time progress for the most serious conditions, and ensure resources are being appropriately allocated.

### The Government should create a 'Pharmacy First for eye care'.

Optometrists in the community are highly skilled and work in every locality in England.

Our survey shows overwhelming public support for better using this capacity through models such as Optometry First, where optometrists and their teams support patients before and after hospital care.

The Government must unite existing community eyecare schemes with new national initiatives that are well communicated with the public.

Expanding the use of optometrists through clear and appropriate new pathways could achieve multiple benefits: improving the efficiency and accuracy of diagnosis, reducing the need for hospital attendance, improving patient outcomes by reducing overall waiting times, and improving people's experience of waiting.

### Support and communication for patients while waiting must be improved

Our survey tells us that support while waiting was not known about or drawn upon by most patients while for many, their sight deteriorated. This situation must improve, particularly for disabled people, including people with learning disabilities who have a significantly higher likelihood of serious sight problems.

Eye Care Liaison Officers, (ECLOs) are a Royal National Institute for the Blind (RNIB) programme that provides vital support to those diagnosed with a condition that affects their sight. Their positive impact is well documented, but the programme is not available to all

patients. We support RNIB's and the UK Ophthalmology Alliance's call for trained and qualified ECLO services to be available for all ophthalmic centres. In England, the current ECLO coverage in the top 150 ophthalmic centres is 71%. The NHS should ensure trusts and other commissioners and funders of eye care services support the increase and sustainability of the funding of this programme alongside RNIB, with universal access as the ultimate aim.

Information on current waiting times, who to contact and key things to look out for should also be readily available via the NHS App.

### Conclusion

Our survey results on people's experiences of eye care show that more could be done to support those waiting to access these services.

Our work is based on a self-selecting sample and reflects the experiences of people who chose to respond. However, the inputs come from a wide geographic spread across England. The fact that we heard from so many older adults perhaps speaks to the nature of the eye conditions people were seeking treatment for – cataracts and glaucoma – both of which are more likely to affect older people.

For the most part, people prefer to access the NHS as their first port of call, even if a proportion have sought private care in the past. Cost plays a part in this decision, but so does the personal choice to stick with NHS services. When people accessed private care, those who had sought specialist eye care in the last two years most often had to borrow money to do so.

Waiting times vary from several months to over a year, and our survey shows that these long waits have detrimental effects on people's lives. Therefore, if waits continue to increase, there may be implications for other health services.

Support for people waiting for NHS care has become a more prevalent issue in recent years. However, we found that not enough was being done to help people waiting for eye care. It may be that people are unaware of what is on offer. Either way, improved awareness and support would be welcome.

### healthwatch

www.healthwatch.co.uk

t: 03000 683 000

e: enquiries@healthwatch.co.uk

**a** @HealthwatchE

Facebook.com/HealthwatchE