

**“Staff are excellent but the
volume of need is very high”**



**People's experiences of eye care
services in Oxfordshire**

September 2024

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Executive summary

Background

This report summarises the results of a Healthwatch Oxfordshire study of primary and secondary eye care services in Oxfordshire. It focused on people's experiences of appointments, information and communication, referral to a specialist service, quality of care, and support to manage an eye condition.

We ran an online survey asking people in Oxfordshire to share their thoughts and experiences of using eye care services in the previous two years. We analysed the results of 141 survey questionnaires from people with different demographic characteristics across Oxfordshire's five districts.

Summary of results

71% of people had visited a community or high street optician and 53% received care at the Oxford Eye Hospital (John Radcliffe or Horton hospitals). 18% had used a private eye care service directly (sometimes to avoid long waits or delayed treatment) or for NHS-paid treatment, and 9% saw their GP. A smaller number of survey participants said they had used any of the other eye care services.

People were generally positive about their experiences of appointments at eye care services: 68% responded 'good' or 'very good' for 'availability of appointments', 64% for 'waiting time for an appointment', and 73% for 'convenience of appointment time'. People were slightly less positive about their experiences of travelling to appointments, costs of care, and referrals.

We heard that availability of appointments at the Oxford Eye Hospital was generally good, although people also experienced cancelled appointments, difficulty with transport and attending early appointments, busy waiting areas, and long waits to be seen. Some were frustrated at not being able to receive outpatient eye care at their local health facility.

Patients rated aspects of service quality highly, citing excellent experiences of care at the Oxford Eye Hospital. Most staff were viewed as considerate, kind and caring, with some providing outstanding care. However, crowded outpatient waiting areas, delayed appointments, and a perception of inadequate staffing left some people dissatisfied and concerned about patient safety.

We heard that communicating with the Oxford Eye Hospital was often difficult, especially about appointments and hospital arrangements. Appointment letters were sometimes poorly written, confusing, or contained incorrect information, others were not patient-friendly or were not adapted to people with additional needs. Feedback on how well eye care professionals explained eye tests and medical procedures was generally positive for both private and NHS providers.

Few people reported receiving support either because they had learned to live with their condition or did not currently perceive a need. Some had received support to manage their eye condition or sight problems while fewer had received advice or support to help them in their daily lives (e.g. with work or at home), to use eye care services (including transport and access to language services), to deal with the emotional aspect of having

an eye problem or sight loss, or to have an active social life and enjoy leisure activities.

Views on how well eye care services worked together to provide treatment were mixed, with people experiencing both integrated and fragmented care. Several people said they had experienced quick referral times to NHS-commissioned providers for cataract surgery and for urgent referrals to the Oxford Eye Hospital. However, people commonly experienced excessive problems after being referred to the John Radcliffe hospital for non-urgent treatment including multiple cancellations or rescheduling of referral appointments, lost or incomplete referrals, and lengthy waits. The COVID-19 pandemic, doctors' strikes, low capacity and administrative errors were all given as reasons.

Recommendations

For commissioners and providers, including: Buckinghamshire Oxfordshire and Berkshire West Integrated Care Board (BOB ICB), Oxfordshire Local Optometric Committee, Oxford University Hospitals NHS Foundation Trust, and private providers of NHS services across the health system

- Review communication processes (with input from patients) and ensure staff are trained and resourced to make reasonable adjustments to improve accessibility for patients, including accessible information and practical adjustments for patients with sensory or physical impairments.

- Improve access to eye care services for people from ethnic minority groups and those whose first language is not English, ensuring access to interpreting services and translated written materials.
- Review (with input from patients and community and voluntary organisations supporting people with sight loss or visual impairment) current provision of advice and signposting to improve support for people living with sight loss.
- Explore the barriers to joined-up working and promote communication and collaboration between different providers and services with a view to improving patient experiences of the referral system.

For Oxford Eye Hospital and associated clinics (Oxford University Hospitals NHS Foundation Trust)

- Review (with input from patients) the process for contacting patients, and the accuracy, accessibility and content of patient communication relating to appointments, including timings, cancellations, communication with those who need interpreters, and what to expect.
- Continue to deliver eye care through local health services and explore the potential to expand outpatient care to community-based clinics. This would reduce barriers for patients who face challenges with distance and travel.
- Stagger clinic timings and offer timeslots where possible (for example, cataract surgery) to improve choice and reduce overcrowding and long waiting times.

- Establish a designated 'drop-off point' in a suitable place to help reduce risks and inconvenience to patients attending eye appointments or treatment.

1 Background

More than 2 million people in the UK are living with sight loss,¹ and around 24,000 people in Oxfordshire have a problem with their sight.² This report summarises what we heard about people's experiences of primary and secondary eye care services in Oxfordshire. We asked about getting appointments, information and communication, referral to specialist care, the quality of consultations and treatment, and any additional support provided to manage an eye condition.

Eye health and sight have an important influence on many aspects of life. Having access to the right eye care service is crucial for diagnosing and treating eye health problems, which are one of the main reasons people in the UK use health care (for more detailed information, see **Appendix 1**).

In Oxfordshire, eye care is provided across primary and secondary care services. Primary care includes GPs, high street opticians, and private and specialist services; secondary care providers include the Oxford Eye

¹ RNIB, 2023, 'The Eye Care Support Pathway' report, available here:

<https://www.rnib.org.uk/your-eyes/the-eye-care-support-pathway/>

² www.myvision.org.uk/

Hospital based at the John Radcliffe Hospital by Oxford University Hospitals NHS Foundation Trust and a centre at Horton Hospital as well as outpatient clinics in community hospitals and other settings across the county. Private clinics also provide some specialist services. The Oxfordshire Minor Eye Conditions Service (MECS) is a relatively new NHS-commissioned scheme that aims to improve access to eye care for people with recently occurring minor conditions through assessment and treatment at accredited community optometrists.³

2 Methods

Between the end of March and May 2024, Healthwatch Oxfordshire ran an online survey asking people in Oxfordshire to share their thoughts and experiences of eye care services.⁴ People were reached through the following:

- Healthwatch Oxfordshire news brief
- Social media, including X (formerly Twitter) and Facebook
- Posters and an article sent to Oxfordshire Local Optometric Committee and Oxford University Hospitals to share with their networks
- A poster and article sent to local Patient Participation Groups

³ https://bucksoxonberksw.icb.nhs.uk/media/4312/primary-care-strategy-final-21_05_24.pdf

⁴ Unfortunately, we were unable to increase the size of the text in the online survey questionnaire, which some people had difficulty reading. We apologise for this and the problem has now been fixed.

- An article sent to and included in the Oxfordshire Association of Local Councils newsletter, and local parish news
- An article included in OCVA newsletter and website, and on the Live Well website
- Information was also sent to Oxford Over 50s, Age Friendly Banbury, men’s health groups, and others.

Most survey questions involved ticking a box from various options and a text box to comment on personal experiences. People were also invited to leave their contact details if they were interested in telling us more about their experiences in a short telephone interview.

After closing the survey, responses were checked for consistency and completeness. A Healthwatch Oxfordshire volunteer carried out telephone interviews with five people, which were written up, removing names and any other identifying information, and used to complement the survey.

3 What did we hear?

3.1 Survey participants

This report includes the results of 141 survey questionnaires.⁵ A summary of participant characteristics is given below. **Table 1** summarises participants by their age group.

Table 1. Survey participants by age group (125 responses)

Age group	Number	Percent
18-24	0	0%
25-49	14	11%

⁵ Note that not all survey participants answered every question.

50-64	38	30%
65-79	44	35%
80 or over	24	19%
Prefer not to say/no answer	5	4%
Total	125	99%*

*Note: Total is less than 100% due to rounding

As expected, most people were in the middle and older age groups (between 50 and 79 years or over) as they are more likely to experience problems with eye health and eyesight. In total, 97 women (77%) and 23 men (18%) responded to the survey, while 6 people (5%) preferred not to identify their gender.

Table 2 below summarises participants by their ethnic group.

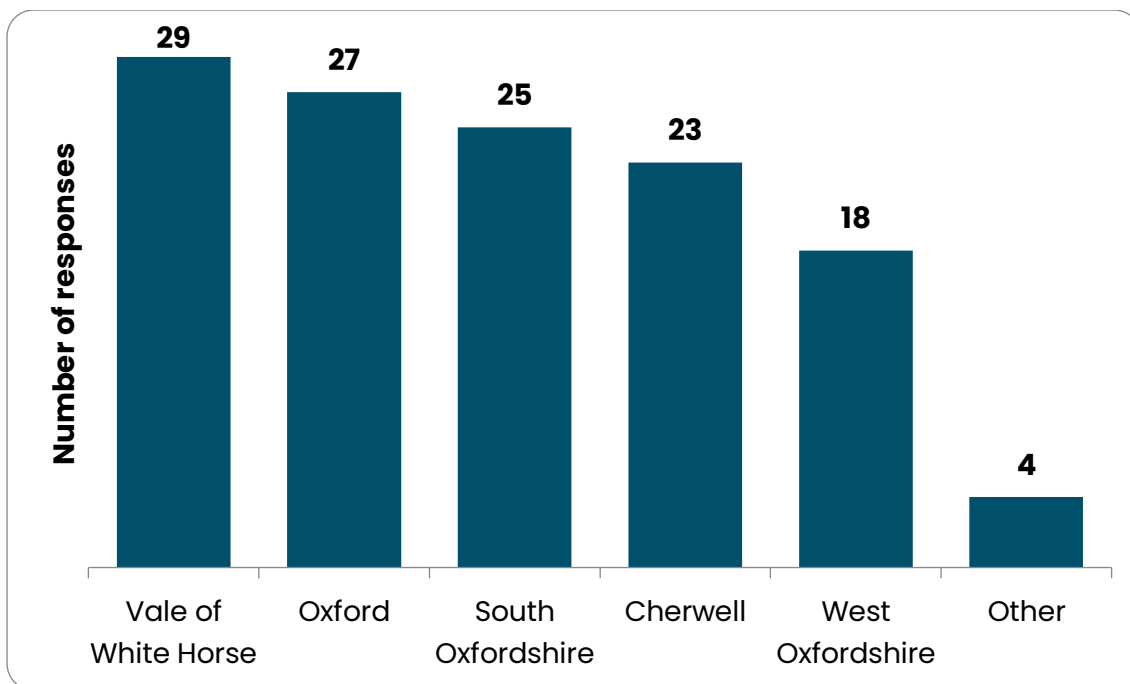
Table 2. Survey participants by ethnicity (126 responses)

Ethnicity	Number	Percent
White: British/English/Northern Irish/Scottish/Welsh	104	83%
White: Any other White background	6	5%
Black/Black British: African	3	2%
Asian/Asian British: Indian	3	2%
Mixed/Multiple ethnic groups: Any other Mixed/Multiple ethnic groups	2	2%
Black/Black British: Caribbean	1	1%
Other ethnic group	3	2%
Prefer not to say/no answer	4	3%
Total	126	100%

Most people (n=104; 83%) said they were White British, while fewer people responded from 'other white', Black, Asian, mixed, or 'other' ethnic groups. Four people did not disclose their ethnicity.

Figure 4 below shows the number of survey participants by Oxfordshire district.

Figure 1. Survey participants by district (126 responses)



Survey participants came from across Oxfordshire’s five districts, although slightly fewer were from West Oxfordshire than other areas. Four people lived in neighbouring counties (Northamptonshire, West Buckinghamshire, and Warwickshire) but had used eye care services in Oxfordshire.

The following sections summarise what we heard in the survey and interviews. Overall, the picture is quite complex, with people reporting a range of views and experiences of their eye care journey with different services and providers.

3.2 What were people’s eye care needs and what did they do?

We asked people to tell us about any eye care problems or concerns they had **in the past two years** and whether they had sought advice or treatment from any eye care service.

Figure 5 below summarises the responses from 141 people.

Figure 2. Have you had a concern or problem with your eyesight? What did you do? (141 responses)

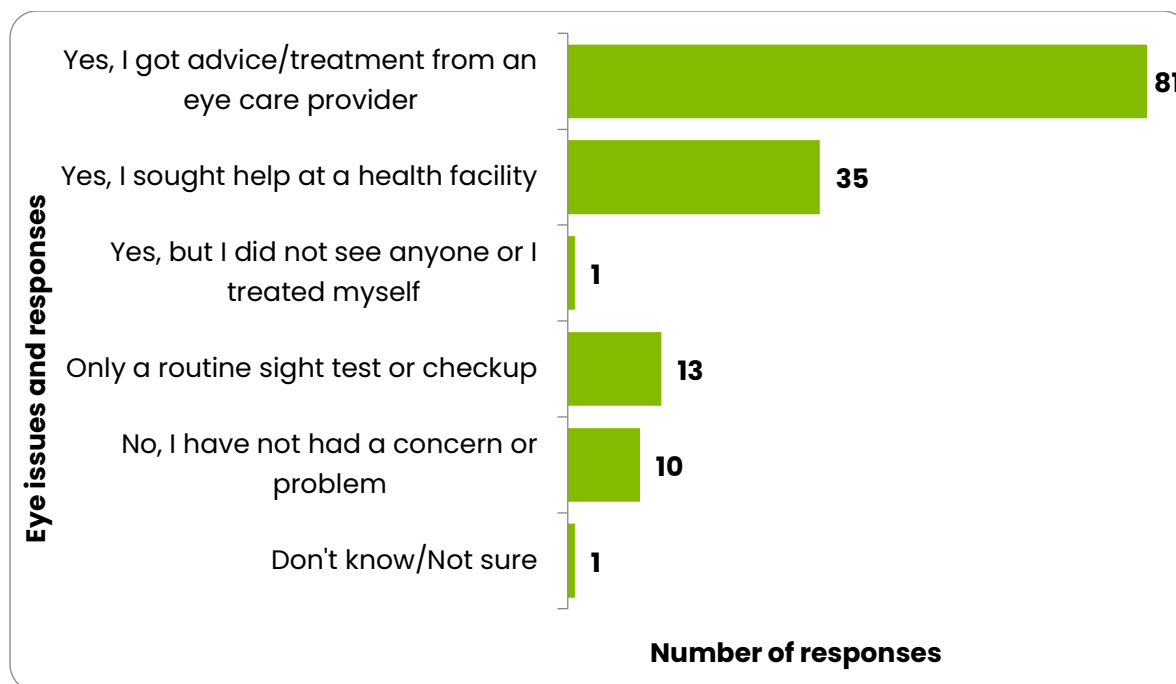


Figure 5 shows that a total of 117 (83%) people said they had experienced an eye health or sight concern (i.e. answered 'Yes'). Of these, 81 (57%) sought advice or treatment at an optometrist or a high street optician and 35 (25%) sought treatment at an NHS hospital or private clinic. Thirteen people (9%) visited an eye care service either for a routine eye test or only for monitoring of a previous condition or treatment (e.g. glaucoma, cataracts).

Ten people said they had not experienced any concerns or problems in the previous two years but contributed useful knowledge of eye care from previous experiences, therefore are included in this report.

We asked people to tell us which eye care services they had used in the past two years, as shown in **Figure 6** below. Note that some people used more than one service.

Figure 3. In the past two years, which of the following eye care services have you used? (126 responses)

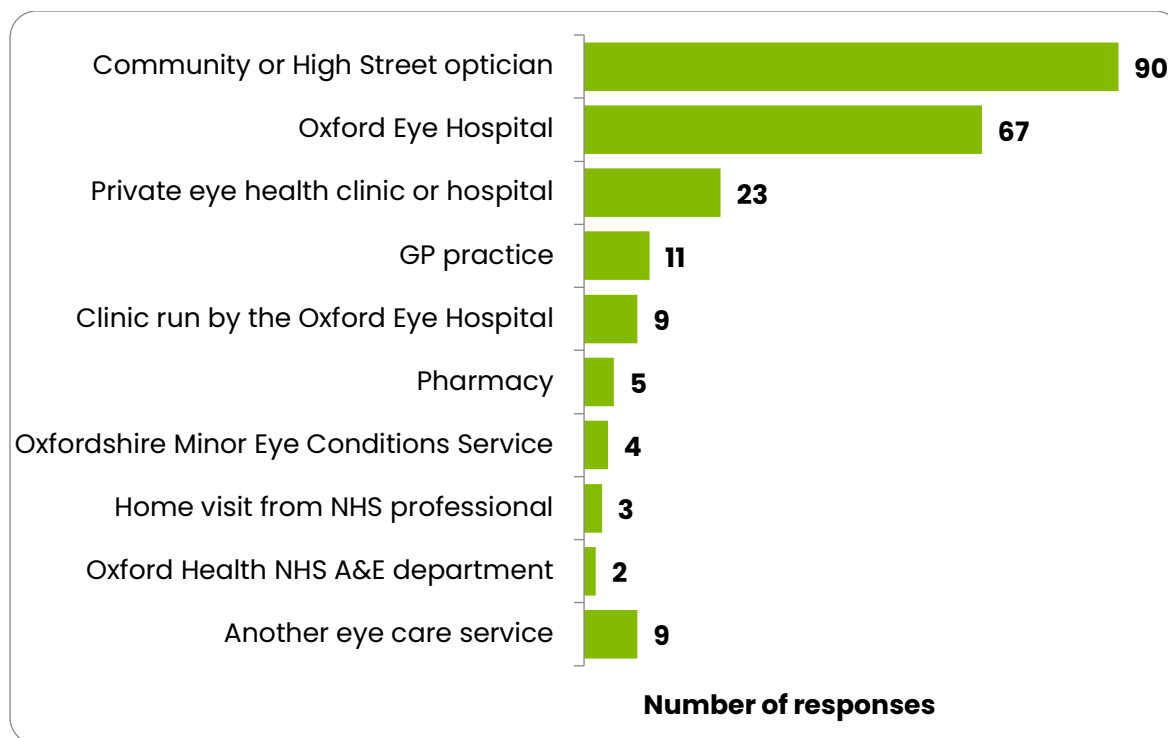


Figure 6 shows that 71% (90 out of 126) had visited a community or high street optician and 67 (53%) received care at the Oxford Eye Hospital (John Radcliffe or Horton hospitals). Twenty-three people (18%) used a private eye care service directly or for NHS-paid treatment, and 11 (9%) saw their GP. A smaller number of survey participants said they had used any of the other eye care services. Nine people (7%) said they used another service but did not necessarily name it.

3.3 What were people’s experiences of eye care?

We asked people about their experiences of **four main areas** of eye care: appointments, quality of service, communication and information, and support to manage their eye condition. People rated each area on a scale from ‘Very Poor’ to ‘Very good’. The results are presented in the following charts.

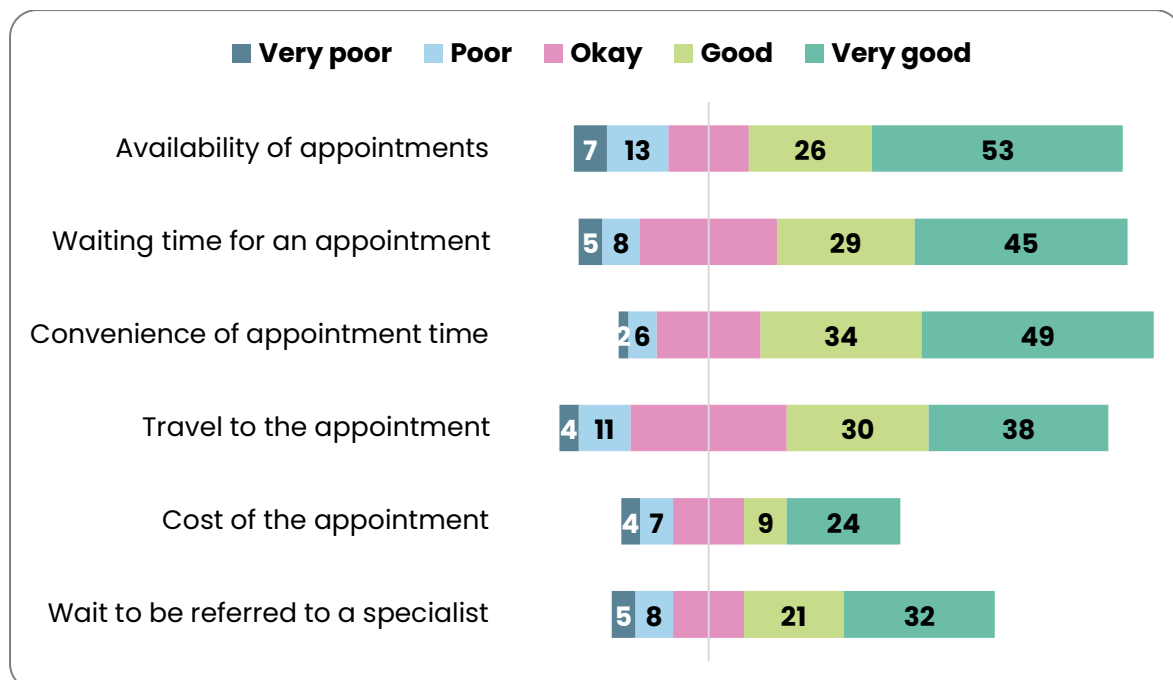
3.3.1 Eye care appointments

People rated their experiences of eye care appointments in **six categories**:

1. Availability
2. Waiting time
3. Convenience
4. Travel
5. Costs
6. Wait for a referral appointment with another provider (e.g. a specialist).

The results are shown in **Figure 7** below.

Figure 4. How would you rate your eye care appointments?



The coloured bars in **Figure 7** range from negative experiences (‘Very poor’ or ‘Poor’) on the left, the neutral ‘Okay’ response with the vertical line running through it, and positive experiences (‘Good’ or ‘Very good’) on the right. Responses ‘Don’t know’ or ‘Not relevant’, are not shown in the chart and explain the shorter bars (e.g. cost of the appointment).

The results show that people were generally positive about their experiences of appointments at eye care services. For example, 79 out of 116 responses (68%) rated 'availability of appointments' 'good' or 'very good', 64% for 'waiting time for an appointment', and 73% for 'convenience of appointment time'. People were slightly less positive about their experiences of travelling to appointments (59% 'good' or 'very good'), and about costs and referrals, although fewer people responded to these last two questions (hence the shorter bar in the chart). However, people's experiences of eye care appointments differed across services, and are explored below.

Availability and waiting times

We heard that availability of appointments at the Oxford Eye Hospital (Oxford University Hospitals NHS Foundation Trust) was generally good, especially in urgent cases:

"Availability of appointments seemed ok and I didn't have to wait too long." (Survey participant)

"I attend the optometry clinic at the JR. I wear scleral contact lenses and if I have a problem I am seen very quickly, often the next day. If necessary I am sent straight across to ophthalmology and fitted in." (Survey participant)

However, several people told us that their appointments at the Eye Hospital had been cancelled. Among the reasons they gave were poor administration, doctors' strikes, and the impact of the COVID pandemic:

"One of the biggest problems is the chaotic nature of the appointment system. At one point I had my operation cancelled

over three weeks before the date but was not notified it had been cancelled so turned up. I had a phone call for a pre-op assessment that I had not been told about and was on a bus at the time. I have had two appointments cancelled whilst I was enroute to the appointments.” (Survey participant)

“I got to the point where I was given an appointment for the surgery. But I had quite a complex issue because I'd had laser surgery before, which meant that it wasn't straightforward to do the cataracts to give me good vision... But I essentially got dumped after COVID, during and after COVID. And I think that because they felt my readings were good in the sense that, you know, it looked as though I had decent vision, even though I had cataracts, I just got dumped quite unceremoniously, quite honestly. So I went from literally having an appointment – and I was astonished and impressed by how quickly I got that – to not having anything and just being dumped!” (Interviewee 1)

As the above examples show, patients felt let down when their appointments were cancelled with little notice or when alternative dates are not given.

Some people said they had difficulty accessing appointments through the Minor Eye Care Service (MECS) scheme:

“Experience was good at A&E Eye Hospital after phoning helpline, hard to get same day MECS appointments.” (Survey participant)

“The other thing I've done in the past is when I've got the symptoms of CMV, rather than go to my GP, I go to certain participating opticians (in the scheme) and I went to [an] eye centre and there's a fantastic optometrist there, and I first went to him when I needed

reading glasses. Trouble is he's not there every day, so if you're lucky you hit the day when he's there." (Interviewee 4)

Other people told us that appointments at most high street practices and private eye clinics were more readily available and that they could usually get an appointment quickly.

Convenience and travel

Convenience of appointments generally meant flexibility in timings and ease of travel and parking at a nearby health facility:

"I attend the macular clinic and I've had two injections... the optometrist who also works in the AMD clinic has now got me going for check-ups at [a closer] hospital, which is fantastic because it takes all that pressure off of trying to get into Oxford and the parking. In [closer hospital] you can park easily in local residential roads and it's just really easy. Inside there is huge waiting space and it's very organised. You get seen promptly and it and it all works so well." (Interviewee 4)

Several people said they wanted some choice in the location and timings of their eye care appointments, to reduce inconvenience and avoid disruption to their routines:

"It was very important that I had the choice to attend the Horton Outpatients and not Oxford. I am working and have to fit in to working shifts. The cost of travel is also a factor for many." (Survey participant)

Given that some eye conditions and sight problems are related to age, it was not surprising that people who travelled quite far to their appointments, did not drive, or relied on public transport said they found it

more difficult to attend appointments that involved travelling far or attending early appointments:

"I have to travel to JR and I live in Banbury. 9am appointments are a nightmare due to having to get through rush hour traffic. Later appointments are easier but harder to find parking space." (Survey participant)

Some people felt frustrated at having to travel for outpatient appointments rather than going to a local or preferred health facility:

"Given that I live only 5 minutes away from the Oxford Eye Hospital where I have received excellent care over the years for glaucoma and a torn retina, it is a shame that I had to go all the way to Long Hanborough (SpaMedica)." (Survey participant)

"In common with much of Oxfordshire, travel to the JR is extremely difficult, particularly for elderly patients. This issue is particularly frustrating as Chipping Norton is fortunate in having a new hospital in the town. Much more use could and should be made of this facility, if only for initial outpatient clinics." (Survey participant)

In contrast, most people who chose or were referred to a nearby or preferred eye care service found it easier and more convenient.

Attending appointments

Common reasons for negative feedback regarding appointments at the Oxford Eye Hospital at the John Radcliffe was the high number of people in outpatient clinics, "chaotic" waiting areas, and long waits to be seen:

"In regard to the hospital, I have never seen such busy clinics. I mean, I couldn't find a seat, let alone my husband. And of course, they do ask you to come with somebody because they put drops

and things in your eyes, and you can't drive yourself home and things like that. Honestly, it really did take my breath away how busy it was." (Interviewee 1)

"The JR (John Radcliffe) is too busy, too impersonal, too rushed, moving around different seating zones being forgotten, long, long waiting times. The treatment when you get it is good, it's just the waiting!" (Survey participant)

"The very poor service was the venue itself in that it was noisy, overcrowded, lack of seating and the appointments sessions were very slow." (Survey participant)

Although people understood that demand at the Oxford Eye Hospital is extremely high, overcrowded waiting areas and delayed consultations had consequences on patient care and overall experience:

"The length of wait was unacceptable in the waiting area. The last appointment was scheduled for 9.15am and at 12.30pm, after chasing the appointment, we were seen and the clinician spent no more than 3 minutes checking my eyes. We had also had multiple on-the-day cancellations of appointments, which impacted in my care arrangements."

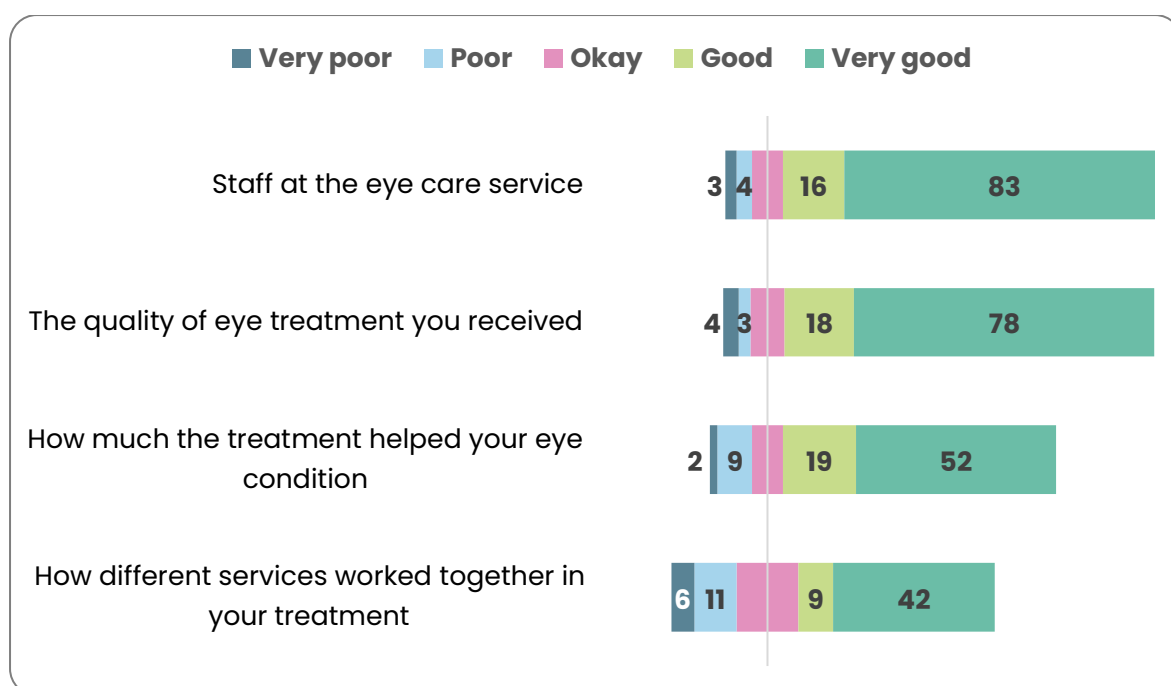
We also heard that some patients' additional needs were overlooked, adding to a negative care experience:

"When attending the Eye Hospital I was asked to sit on the chair for eye exam - it is clear I am in an electric wheelchair with significant disability...Specialist had a poor attitude and was very rude about not sitting in their chair. I need to be hoisted in and out of my chair." (Survey participant)

3.3.2 Quality of services

People were asked about their views on the quality eye care services, in terms of staff, medical treatment, how the treatment had helped their eye condition, and how well different eye care services had worked together to provide care (e.g. for referrals). **Figure 8** summarises the results.

Figure 5. How would you rate the quality of eye care services?



The figure above suggests that, overall, people considered the quality of eye care services to be 'good' or 'very good': 87% for staff, 80% for the quality of treatment, and 79% for the effectiveness of treatment. Fewer people felt that the various eye health services involved in their care had coordinated well with each other to deliver effective care.

Feedback in the comments sections of the survey confirmed that many people clearly had excellent experiences of eye care at the Oxford Eye Hospital. Typical survey feedback included:

"The care provided by the eye hospital team has been of a high standard." (Survey participant)

"Since transferring to Oxford Eye Hospital I could not have received better care." (Survey participant)

"[John Radcliffe] eye hospital absolutely fantastic cannot fault."
(Survey participant)

However, crowded outpatient waiting areas, delayed appointments, and a perception of inadequate staffing to meet the high demand left some people feeling dissatisfied and concerned about patient safety:

"Staff are excellent but volume of need is very high...Feels like operating on sparse staff." (Survey participant)

"I would not recommend the eye hospital to anyone as I don't feel it can cope with the demands put on it or it is safe for patients."
(Survey participant)

Health service staff

We heard that eye health providers were usually polite and professional towards patients. People appreciated feeling valued by staff and being "treated as a person, not just a number." Positive feedback also focused on staff who were considerate towards patients and their circumstances, kind and caring. One Oxford Eye Hospital patient was grateful to their consultant for their understanding and helpful attitude:

"... she was very considerate and took special care in arranging an injection at short notice." (Survey participant)

Many people commented that, despite working in a busy and demanding environment, staff at the Oxford Eye Hospital provided excellent care and tried their best:

“The kindness and friendliness of every member of staff has been unflinching, even though they were so busy.” (Survey participant)

People who gave mixed or negative reflections on their interaction with eye care staff also focused on their attitude and behaviour:

“... the [high street] optician was the rudest person I have ever had the misfortune to have an appointment with, so I went to [other high street optician] - my goodness what a difference, they were kind understanding and helpful.” (Survey participant)

Eye care treatment

Positive feedback focused on efficient diagnostic tests, perceived high quality of optical equipment, the range of treatment options, accuracy of diagnosis, and extremely quality of clinical treatment:

“My husband has been receiving AMD treatment at OUH (Oxford University Hospital NHS Trust). This service has been impeccable. He has also had retinal detachment surgery recently, also excellent same day surgery.” (Survey participant)

“I go to ophthalmology and optometry at the JR (John Radcliffe), at the Eye Hospital. I find them absolutely amazing, particularly the optometrist. If I've got a problem, I can e-mail her. For example, two weeks ago I realised I had a blood vessel in my left eye that was bulging, and she told me to come in the next day at the end of children's clinic. I mean, she's just amazing and if she thinks it's something urgent then she will just take my file and pop me through

to ophthalmology and put me at the end of their clinic list. Phenomenal." (Interviewee 4)

A small number of people who used private practices and NHS services reported experiencing poor quality care. These included misdiagnosis of eye problems, near misses, and clinical mistakes:

"Recently [a high street] optician...decided the problem was my lens fit having only spoken to the person on the desk who asked me a few questions and relayed this back to me. In my experience local opticians have rarely even seen a scleral contact lens, let alone know how to fit them...The problem was an enlarged blood vessel, diagnosed at the hospital." (Survey participant)

"... the surgeon [private NHS-commissioned provider] who did my eye was not [ok] - he did a lot of damage to my eye and the follow up was poor... The problem was that it took too long to see a second surgeon 4 days later and the damage done to my eye was made worse... I will never go to one of these 'do it quick' clinics again. If all goes well it is fine but when it doesn't, the back-up is just not there." (Survey participant)

Effectiveness of eye treatment

Relatively few people commented on the effectiveness of their eye care. Most of those who did give feedback had undergone cataract surgery and said it had not only improved their sight but also their quality of life. One patient related a positive outcome to an effective sequence of referrals from their optometrist to the Oxford Eye hospital and onto a private NHS-commissioned service at a private clinic:

"Very joined up service that put the patient (me) first... thanks for providing me with an excellent service that enabled me to continue

enjoying an improved vision that enhanced my quality of life.”
(Survey participant)

Another patient who received treatment at the John Radcliffe hospital for glaucoma commented:

“The eye hospital staff have been key to my improved vision through thoughtful and professional management of my conditions.” (Survey participant)

Integration of eye care services

Views on how well eye care services worked together to provide treatment were mixed, with people experiencing both integrated and fragmented care. The patient in the extract above reported a “Very joined up service”, while some said they experienced good coordination between their community optician and their GP. However, others reported delays and confusion between providers across private and NHS sectors:

“Obviously no join up between private and NHS [services] which causes confusion.” (Survey participant)

Other comments on the quality of services

There was an awareness of the pressure that NHS services are currently under, with constrained resources and demanding conditions in which staff are working:

“I think the service providers are well qualified, working very hard to manage a busy department, with a low capacity of staff and building.” (Survey participant)

“I don't feel it can cope with the demands put on it or it is safe for patients. The staff are all under huge amounts of stress by the volume of work.” (Survey participant)

One person commented on a lack of continuity at the Oxford Eye Hospital, where they were attended by different members of medical staff on each visit. Some people were disappointed when they were seen by someone other than their specialist consultant:

"The consultants are busy with their private patients. I can't believe in the last 10 years of going to the Oxford Eye Hospital, I have only been seen by the consultant in about three occasions... you never see the same person twice even though I come to this hospital every four months."

"Staff always very efficient and kind. Would like occasionally to see a consultant rather than a nurse practitioner." (Survey participant)

We heard that people who used private eye care services sometimes felt uncomfortable with the variation in prices between different high street opticians or when providers offered extra services they had not asked for:

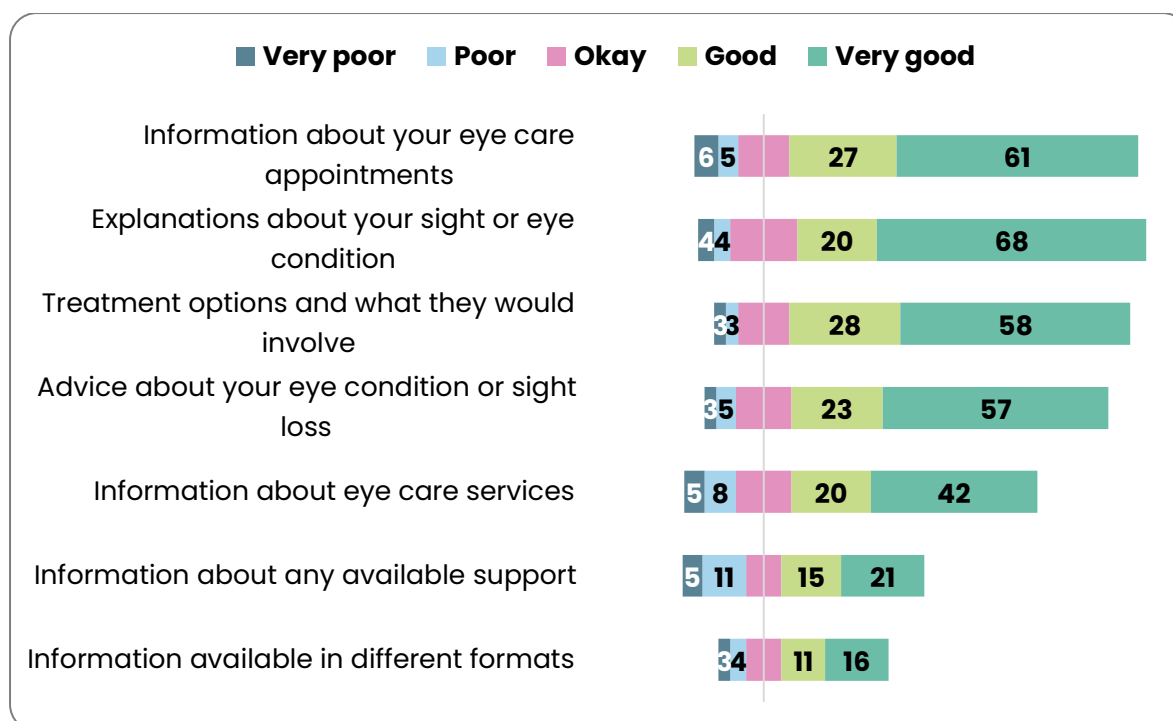
"I object to pressure being put on high street customers to buy services such as hearing tests which are irrelevant to any eye problems." (Survey participant)

"The costs varied across various providers and most seemed to be tied to certain offers from the provider. It was not completely reassuring to have such an important examination at a provider with potential commercial bias as opposed to an examination at an NHS health facility free from bias." (Survey participant)

3.3.3 Communication and information

A third category of experience asked people about aspects of communication and information from eye care services. The results are summarised in **Figure 9** below.

Figure 6. How did you experience eye care communication & information?



As the figure shows, overall, people rated most aspects of communication and information from eye care services as good or very good (i.e. 88 out of 113 responses (78%) for information about their eye care appointments, 78% for explanations about sight or eye condition, 82% for information about treatment options, and 79% for advice about their eye condition). Fewer people responded to the other aspects of communication and information but were generally more positive than negative.

Information about eye care appointments

People appreciated good communication throughout their eye care journey, including information about appointments and explanations of treatment procedures. Examples included timely appointment letters from the Oxford Eye Hospital and information sent in large print and confirmation text messages, which they mainly received from high street and private providers.

However, we heard that communicating with the Oxford Eye Hospital was often difficult, especially about appointments and hospital arrangements:

“The whole patient care system is impossible to penetrate. Administration is variable. Key administrators are very difficult to contact. Promises of return phone calls almost never fulfilled.”
(Survey participant)

“Staff communication was generally excellent but information about my appointments was very variable.” (Survey participant)

Some people said that appointment letters were sometimes poorly written while others were confusing or contained incorrect information:

“Yesterday I received an appointment letter for a second injection in June, and this morning have received a second appointment letter for one in May - no information as to whether that is two appointments or the second is instead of the one in June.” (Survey participant)

“Paperwork giving incorrect information about travel to the hospital and also payment for car parking.” (Survey participant)

In the following interview extract, a patient describes receiving a letter with incomplete or incorrect information about their appointment and how they should prepare for it:

"I have very mixed feelings about them. The admin around them was atrocious. I have to say absolutely appalling. The letter regarding my [initial] appointment said absolutely nothing about having to have the eye drops that dilate my pupils. Which it should, because if you've got dilated pupils, you can't drive, and we don't all live on easy bus routes... And so, I took it upon myself to ring the hospital the morning of my appointment and asked whether I would be having drops to dilate my pupils? Because if I am, I need to find another way of getting to Oxford from where I live. And some chap said, "Oh, no, no, we won't be doing that." Well, guess what? They did give me the drops. They dilated my pupils, but by that time I'd driven there. I mean, it was a nightmare.

My appointment was [in the afternoon] and you have to arrive early because the traffic to Oxford and the parking is just diabolical. I think everybody in the world knows that by now! I only waited a few minutes before the nurse called my name and I went through for some tests on my eyes and that's when I discovered I was going to have them dilated. And she said that I had to have the dilation otherwise they couldn't do the test and I'd have to go home. Well, actually it turned out that that was incorrect... So that was a learning issue, and that's fine. You know, I don't object to that. We all do things like that when we're new to a job, simply because we don't know the processes and procedures, so that's fine." (Interviewee 2)

Some people felt that communication from the Eye Hospital was not patient-friendly or was sometimes not adapted to individuals' needs. For example, a British Sign Language speaker from the deaf community said

they had received a 'no reply' text message that would not allow them to respond to the message. Another received a letter asking them to telephone the Eye Hospital. Since neither patient could converse on the telephone, these communication methods were inaccessible and they were unable to respond themselves.

"I had a letter from the Eye Hospital it told me to ring them - but I can't ring them I can't communicate that way. I'm waiting for surgery so it's really important that I get the information in a way that is accessible to me" (direct comment)

Explanations about sight problems or eye conditions

Some people described receiving useful information packs before cataract surgery date explaining the procedure as well as giving post-operative advice and instructions for self-care. While people valued being kept informed, medical terms sometimes confused or concerned patients. One person who was referred to the Oxford Eye Hospital said:

"I am now very pleased that after an appointment, a letter is sent to me detailing my eye condition. I don't necessarily understand the terms which can sound alarming so will discuss this with the doctor at my next appointment. It helps, I feel, to keep me better informed and prepared." (Survey participant)

Another person told us they had found it difficult to get information from a high street provider about their eye condition (macular hole) and who said they had not been informed early on about their eye condition:

"Apparently macular hole seen on [initial scan]. I wasn't told that. Then vision became blurred...and told had macular hole. Why wasn't I told in September? Why was it left to get so bad?" (Survey participant)

Feedback on how well eye care professionals explained eye tests and medical procedures was generally positive for both private and NHS providers:

“Each member of staff I saw explained what they were going to do and gave advice where necessary.” (Survey participant)

“Consultant is excellent, explains everything clearly and gives time for questions.” (Survey participant)

Most people who commented on staff at the Oxford Eye Hospital clinical described receiving clear and comprehensive explanations of eye conditions and medical procedures:

“I probably know more than most about what happens, and they do explain things very well. They do explain the procedures – [the consultant] is fantastic and shows me all the scans they do of my eye. So, I've seen what the hole is like at the back of my retina. She shows me all that and shows me where the scar is, where it's closed up and I'm made very aware of what's happening and why.”
(Interviewee 4)

One interview participant compared their experiences of NHS and private care, highlighting the value of providing patients with clear and comprehensive information:

“...my first cataract experience was absolutely fantastic and that was done at the John Radcliffe. But for my second one, they sent me to a private place in [place]. And if that had been my first time, it would have put me off! There is absolutely no communication at all. In fact, my biggest suggestion to the powers that be, is that there needs to be more communication from the surgeons to the patients because the chap in Oxford was fantastic in comparison. The

consultant at the [NHS hospital] went through everything with me, step by step and fully explained.

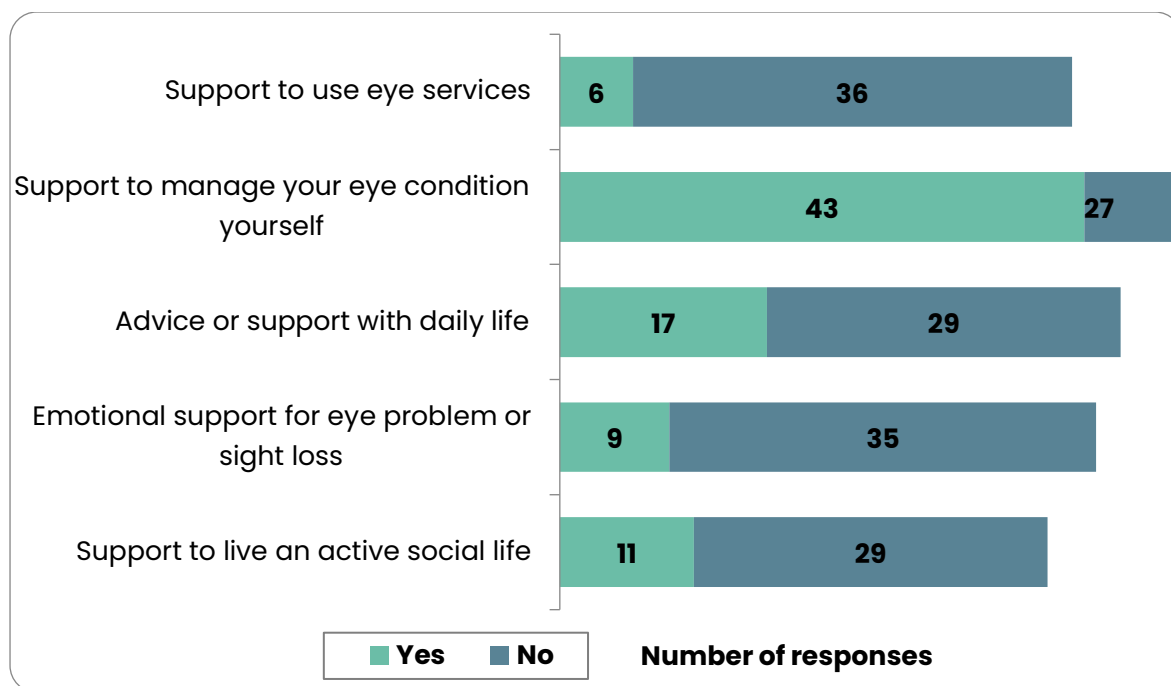
However, the second time, the consultant literally only introduced herself and checked my number, that was it, basically. And it was a different type of procedure that she did. I think it was laser and during the procedure, which she didn't explain to me, she just stuck this thing in my face which was scary. She didn't tell me it was going on or explain what would happen. Anyway, I felt something in my eye, something quick in my eye. And when I said something about it, her manner was as if I was lying! You know, I mean, I said that I can feel something prick in my eye, it's my eye and I know what I can feel! No empathy whatsoever. (Interviewee 5)

Other comments suggested that some high street practices might be sending printed materials that are out of date and other information lacked detail on what to expect after cataract surgery.

3.3.4 Support to manage eye conditions and their impact

We asked people whether they had received any additional support during their eye care journey, including to access services, manage their eye condition, come to terms with their condition, and continue regular activities (see **Figure 10** below).

Figure 7. Have you received any support for your eye condition?



Fewer people responded to this question, either because they had learned to live with their condition or did not currently perceive a need for support. Most people who did answer said they had received support to manage their eye condition or sight problems. However, fewer had received advice or support to help them in their daily lives (e.g. with work or at home), to use eye care services (including transport and access to language services), to deal with the emotional aspect of having an eye problem or sight loss, or to have an active social life and enjoy leisure activities.

A few people told us they had received emotional support from different sources, which helped them cope with impact of their condition:

“I am good at asking for help and the Optometrist at the Oxford eye hospital has been outstanding in supporting me through difficult times.” (Survey participant)

"I had private counselling to help cope with the fact I would lose my driving licence and independence that being able to drive brings particularly as I live in rural village with no bus service." (Survey participant)

"Emotional support from the Macular Society, not from the NHS." (Survey participant)

Practical help from volunteer transport services was also important:

"Transport by Didcot Volunteer Drivers has been invaluable."

3.3.5 Referrals to other eye care services

Eighty people told us they had been referred to another eye care service or specialist by their initial eye care provider. Several people said they had experienced quick referral times to NHS-commissioned providers for cataract surgery. Urgent referrals to the Oxford Eye Hospital were also usually handled promptly:

"Referred to the emergency eye department and the referral was done very quickly and seen the same day." (Survey participant)

"Emergency at the eye hospital at Oxford with uveitis and then developed high eye pressure and urgently referred to [consultant] team for closed angle glaucoma. I was seen very quickly by [consultant's] team. The whole referral process was well managed." (Survey participant)

However, we commonly heard from people who had experienced excessive waiting times after being referred to the John Radcliffe hospital for non-urgent treatment:

"Referred to JR VRT dept for macular hole surgery and told 9-10 month wait time...Waiting for surgery date, meanwhile sight is deteriorating!" (Survey participant)

"The optician's referral asked for an appointment in two weeks, I was sent an appointment for 5 months later. I went back to the optician and they referred me through a different route. Unfortunately, the experience was pretty bad." (Survey participant)

Other people reported experiencing combinations of problems including multiple cancellations or rescheduling of referral appointments, lost or incomplete referrals, and lengthy waits:

"My optician advised my GP that I need a referral to eye services for a procedure following cataract surgery. My GP then contacted OUH for an appointment. Time from eye test to referral appointment being received was several weeks, and only received after chasing. Once appointment was received, for November 2023, I was contacted to be advised the appointment had been changed to December 2023. This appointment was then moved again to April 2024." (Survey participant)

"Was referred by hospital specialist team for laser surgery to reduce IOP. The hospital appointments leading up to the one where decision made for surgery were rescheduled 3 times." (Survey participant)

A few people said their referral for treatment had been delayed because of administrative errors. One person who had been referred to the Oxford Eye Hospital John Radcliffe said:

"My optician did eye test and a scan and referred me to my doctor so that I could be referred by her to the eye hospital for laser

treatment. After 4 months had heard nothing so at my annual [check] at doctor's I mentioned this to nurse. It was found that my optician's email had not been referred to my doctor. The referral was then done and I was referred and was given an appointment in two months' time. This was then cancelled as I had been given an appointment for the wrong clinic..." (Survey participant)

In contrast, people who were referred to an NHS-commissioned private provider experienced prompt access to treatment:

"Referred to Spa Medica at Long Hanborough. The appointment was made quickly, within a week of my appointment at the Opticians." (Survey Participant)

Poor experiences of referral to the Oxford Eye Hospital, such as lengthy delays or cancelled surgery and inadequate communication led some patients to pay for treatment at a private clinic:

"I was referred to the Horton for cataract surgery. I was not happy about the pre-assessment. The surgery was cancelled once. I was not given a date for the second eye to be done but a vague statement that it I would have to wait at least six weeks. I had it done privately, first one eye and the second a week later." (Survey participant)

4 Summary of what we learned

This survey looked at the eye care experiences of 141 people across different services in Oxfordshire. Survey participants were mostly aged between 50 and 79 years, women, and identified as white British. Most

people said they had received care at a community or high street opticians or at Oxford Eye Hospital. Others went to a private clinic or hospital, their GP, or other services.

The survey responses and interviews suggested that most people have a positive experience of eye care overall. Many people appreciated the effort of health care staff, early diagnosis and referral of urgent eye conditions, and the quality of medical treatment. However, others highlighted aspects of care that had negative impacts on patients' experiences. These included challenges travelling to appointments, difficulty parking, "chaotic" outpatient clinics and long waits at busy hospitals, confusing or incorrect information about appointments and eye care procedures, cancelled appointments, harmful treatment, and services not working well together to ensure effective care. Referrals for NHS care were sometimes changed or cancelled, while those to independent and NHS-commissioned private providers appeared to work more efficiently, probably due to a smaller patient load and the treatment of less complicated cases. Some people sought treatment in the private sector because long waits for treatment at NHS hospitals or sometimes because of poor initial experiences. Others saw it as the only way to get treatment in a reasonable timeframe. We also noted that few people appeared to be offered emotional and practical advice and support to adapt to sight loss.

The survey heard from a relatively small number of people and limited responses from younger age groups and men. Also, 83% were from white British communities, although this broadly reflects the ethnic diversity across the county (according the 2021 Office for National Statistics (ONS)

survey, 77% of Oxfordshire's population identify as 'White: English, Welsh, Scottish, Northern Irish or British').⁶

Our study focused on aspects of people's 'journey' through the eye care system. The data suggest a need to improve the quality of information about eye care services and about support that is available to people experiencing eye conditions and sight loss. Current demand for NHS health care, including eye services, has inevitably resulted in longer waits for appointments and treatment, as well as busy outpatient departments. While people understand the effect these demands have on capacity and quality, they also want to receive good service and have a positive experience of care.

The introduction of the National Minor Eye Conditions (MECS) service (commissioned locally by Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board – BOB ICB), should relieve pressure on GP practices, A&E and other hospital eye care services. However, our data suggest that people's experiences with participating providers is mixed.

5 Recommendations

The key areas we heard about where improvements would enhance patient experiences of eye care include:

⁶ See <https://insight.oxfordshire.gov.uk/cms/census-2021-ethnic-groups-oxfordshire>

BOB ICB, Oxfordshire Local Optometric Committee, OUH and private providers across the health system

- Review communication processes (with input from patients) and ensure staff are trained and resourced to make reasonable adjustments to improve accessibility for patients, including accessible information and practical adjustments for patients with sensory or physical impairments.
- Improve access to eye care services for people from ethnic minority groups and those whose first language is not English, ensuring access to interpreting services and translated written materials.
- Review (with input from patients and community and voluntary organisations supporting people with sight loss or visual impairment) current provision of advice and signposting to improve support for people living with sight loss.
- Explore the barriers to joined-up working and promote communication and collaboration between different providers and services with a view to improving patient experiences of the referral system.

Oxford Eye Hospital and associated clinics (Oxford University Hospitals NHS Foundation Trust)

- Review (with input from patients) the process for contacting patients, and the accuracy, accessibility and content of patient communication relating to appointments, including timings, cancellations, and what to expect.

- Continue to deliver eye care through local health services and explore the potential to expand outpatient care to community-based clinics. This would reduce barriers for patients who face challenges with distance and travel.
- Stagger clinic timings and offer timeslots where possible (for example, cataract surgery) to improve choice and reduce overcrowding and long waiting times.
- Establish a designated 'drop-off point' in a suitable place to help reduce risks and inconvenience to patients attending eye appointments or treatment.

Appendix 1. Key facts about eye care

Figure 8. Key facts on eye care and sight loss



More than **2 million** people in the UK are living with sight loss (RNIB, 2023)

More than **8 million** people attend a hospital for eye care each year (RNIB, 2023)



Around **24,000** people in **Oxfordshire** have a problem with their sight (www.myvision.org.uk)

Some people don't get the necessary **information, services, and support**



Appendix 2. Eye care services

A range of health professions provide eye care services and support, as shown in **Figure 2** below.

Figure 9. Types of eye care professional and what they do

Optometrist	Examines people's vision, e.g. sight tests, diagnoses problems, prescribes spectacles
Orthoptist	Specialist in problems with eye movement and the eyes working together, e.g. squints
Ophthalmologist	Eye doctor or surgeon who diagnoses and treats eye problems, e.g. glaucoma, cataracts
Ophthalmic nurse	A specially trained Registered Nurse who provides specialised care to patients with eye conditions and diseases
Dispensing optician	Fits and dispenses spectacles and lenses
Eye Clinic Liaison Officer	Supports visually impaired patients, advocates for patients experiencing sight loss
Ophthalmic genetic counsellor	Supports people with genetic causes of sight loss

According to the NHS, optometrists provide more than **13 million NHS sight tests** across England each year.⁷ In the Buckinghamshire, Oxfordshire, and

⁷ www.england.nhs.uk/primary-care/eye-health/

Berkshire West region, around 400,000 NHS sight tests are carried out each year and approximately 25,000 people are referred to secondary care.⁸

Older people, people with specific eye conditions, prisoners, and those in some poorer groups or who are receiving benefits are often able to get free eye tests and optical vouchers through the NHS.⁹

Ophthalmology is the busiest hospital outpatient speciality and accounts for almost 10% of the entire NHS waiting list. NHS England have recently issued new clinical guidance to improve patients' experiences of eye services and reduce unnecessary referrals to ophthalmology services.¹⁰

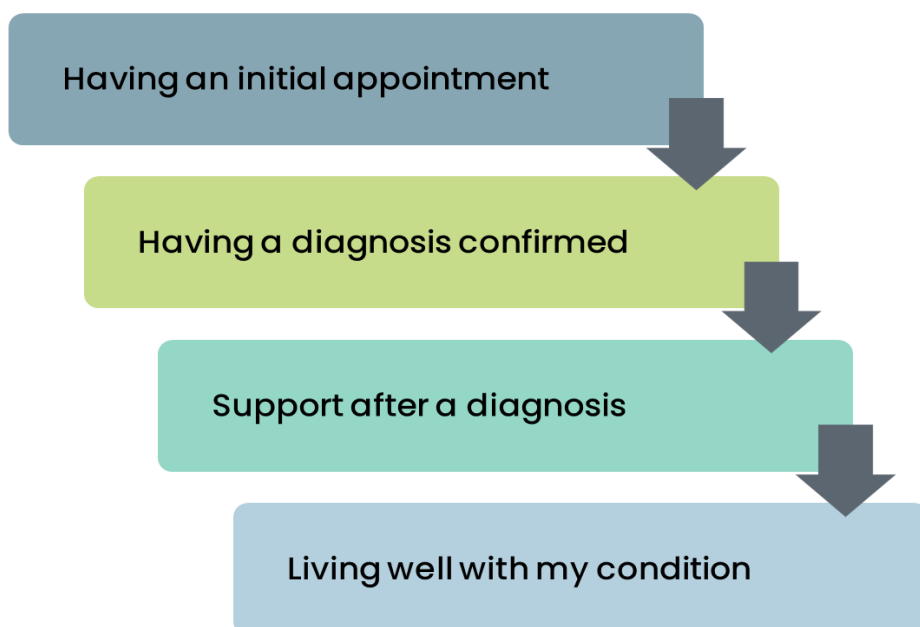
Eye health and sight conditions are not only a 'medical' problem but affect the person in many ways. People experiencing eye or sight problems might need support throughout their eye care journey to manage their condition and lead an active social life. The Royal National Institute for the Blind (RNIB) have developed an eye care support pathway, which identifies four key stages in a person's eye care journey where information and support should be made available. It is summarised in **Figure 3** below.

⁸ https://bucksoxonberksw.icb.nhs.uk/media/4312/primary-care-strategy-final-21_05_24.pdf

⁹ www.nhs.uk/nhs-services/opticians/free-nhs-eye-tests-and-optical-vouchers/

¹⁰ www.england.nhs.uk/2023/05/new-nhs-measures-to-improve-eye-care-and-cut-waiting-times/

Figure 10. Stages of the eye care support pathway



Adapted from: <https://www.nib.org.uk/your-eyes/the-eye-care-support-pathway/>

Throughout these four stages, people using eye health services need to understand their eye care journey, understand their diagnosis, and have access to emotional and practical support.¹¹

In **Oxfordshire**, the main services for eye health are:

- **Community opticians** – do sight tests, can diagnose some problems, dispense spectacles and contact lenses. Commissioned by NHS to provide free services for children, people over 60 and some other patients (<https://www.nhs.uk/nhs-services/opticians/free-nhs-eye-tests-and-optical-vouchers/>)
- **Oxford Eye Hospital** <https://www.ouh.nhs.uk/eye-hospital/>
 - Based at **JR**, with a centre at Horton
 - Eye casualty (emergency)
 - Treatment for cataract, glaucoma, ocular inflammation

¹¹ www.nib.org.uk/professionals/health-social-care-education-professionals/knowledge-and-research-hub/reports-and-insight/peoples-experiences-of-accessing-eye-care-services/

- Children’s Rapid Access clinic
- Specialist optometry
- Specialist orthoptics – including some services as part of enablement or rehabilitation
- Ocular moles service
- **Clinics** run by the Oxford Eye Hospital in community hospitals/local settings:
 - Children’s refraction clinics – monthly/bimonthly in Abingdon, Horton, Bicester, Didcot, Wantage and Witney
 - Optometry clinics – monthly/bimonthly at Horton, Wantage and Witney
 - Orthoptics clinics – clinics several days a week at Abingdon, Banbury, Bicester, Didcot, Wantage, Witney
- **Oxfordshire Minor Eye Conditions Service** – delivered via accredited community optometrists
<https://oxfordshireloc.org.uk/mecs/>
- **Oxford Diabetic Eye Screening Programme** – coordinated by OEH, carried out by community opticians or technicians at GP surgeries. <https://www.ouh.nhs.uk/eye-hospital/odesp/>
- **Rehab services** – delivered by Oxfordshire County Council

Appendix 3. Interviewee case stories

The following five case 'stories' are interviews with survey participants who agreed to talk about their experiences of eye care. Interviewer questions. The interviewer questions are marked as **Q** and interview participants' responses appear underneath. Information that would identify the patient or members of eye care staff have been removed and the transcripts have been slightly shortened to include only the most relevant information to the patient's journey through eye care.

Interview 1. Experience of cataract surgery at the John Radcliffe Oxford Eye Hospital

Q. What concerns or problems did you have with your eyes or eyesight? What did you do / where did you get help?

I've worn glasses for a number of years, but I was getting cataracts, and I went to the hospital. I got referred to the JR (John Radcliffe) for cataracts.

Q. How do you feel about the eye care appointments that you had?

In regard to the [JR] hospital, I have never seen such busy clinics. I mean, I couldn't find a seat, let alone my husband. And of course, they do ask you to come with somebody because they put drops and things in your eyes, and you can't drive yourself home and things like that. Honestly, it really did take my breath away how busy it was.

But what happened at the original appointment...I got to the point where I was given an appointment for the surgery. But I had quite a complex issue because I'd had laser surgery before, which meant that it wasn't straightforward to do the cataracts to give me good vision. I could get rid of blurriness, but they

couldn't guarantee it because I had monovision, so one eye was distant and one eye was near, so there was a complication with it. And because my vision was good at the appointment, in the sense that they thought I could see quite well, but you know, any fool can read the charts. But I essentially got dumped after COVID, during and after COVID. And I think that because they felt my readings were good in the sense that, you know, it looked as though I had decent vision, even though I had cataracts, I just got dumped quite unceremoniously, quite honestly. So I went from literally having an appointment – and I was astonished and impressed by how quickly I got that – to not having anything and just being dumped!

I made the decision after COVID to go private because I thought the pressure on the NHS was so great. I thought I was doing them a favour because their lists were ever so long, they had to drop me off it. And I thought, 'Well, I'm lucky enough in that I can pay for this.' So anyway, I went private, and it was the same consultant but this time costing me two and a half grand.

The last letter, i.e. last communication I got from them (NHS) basically just said if you have any further problems, just contact your GP or your optician. So, I felt I was back to square one and I was convinced I wasn't as bad as lots of people, which is partly why I decided to go private, but I wish I hadn't.

Q. How did you feel about the communication about your eye condition and treatment?

Generally, it was quite good. But there was one letter where they were describing the wrong eye which was a little bit disconcerting. I don't know what, why, or how that happened? Luckily when I was reading it, I noticed they were describing the wrong eye.

Q. What would you like the people who make decisions about health and care in Oxfordshire to know about your experience? What changes would you like to see?

Well, I mean my eye care isn't resolved because I've had all sorts of problems. Basically, because I was awaiting sinus surgery, [the consultant] told me to wait until my sinus issues were resolved and then get back in touch if I was still having the problems. Well, it took me ages to get the sinus surgery and I obviously had to wait for the recovery time, so I've very recently written to [the consultant]. But clearly once he's got his money, he's not that bothered because it's two weeks since I wrote and not even an acknowledgement from his secretary, never heard back.

The only other thing I'd say in relation to care is that while I've been waiting for this sinus surgery, there were a couple of times when I thought I might have had a bit more infection in my eye or inflammation after my op. So I asked to see my Dr as I thought it may have been connected to my sinus thing as well. I just couldn't get past the receptionist because the minute I mentioned my eye, she made me go to the optician at Specsavers. And the opticians were simply not set up for it at all. I mean, I love Specsavers and I see the same person because it's been an ongoing problem since the cataract surgery and I get really good care from them, but they were not set up. It's a bit like, I think, probably how the pharmacies are now. They are not set up to deal with this sort of 'the GP won't see you, so you've got to come and see them' setup.

Interview 2. Experience of appointments and communication at the John Radcliffe Oxford Eye Hospital

Q. What concerns or problems did you have with your eyes or eyesight? What did you do / where did you get help?

I noticed over the last year that my vision was becoming distorted and that in my right eye I could no longer see properly out of the lens. It was very blurry and very uneven so every line that should, in theory, be straight like a doorway was all wavy. It was really quite distorted, so I went to the optician who said I had AMD, which I didn't.

The optician asked my GP to refer me to the Eye Hospital and asked for an urgent referral in two weeks. But of course, that doesn't happen. I mean, it just doesn't happen. And that's not a criticism, it's just an acknowledgment of the fact it just does not happen. But I did query how urgent it really was because the appointment I got was for January and bearing in mind the referral was in August! And I thought, if it's really that urgent, shouldn't I be being seen before January? Or is it maybe not as urgent as he's making out? I don't know, I have no idea.

So, the opticians are different, and they referred me a different way to a different clinic. More directly I think, and the appointment came through much more quickly. So, I was a bit happier that with. So that's how it all came about, and that was the start of my rather long, tedious story.

Q. How do you feel about the eye care appointments that you had?

I have very mixed feelings about them. The admin around them was atrocious. I have to say absolutely appalling. The letter regarding my [initial] appointment said absolutely nothing about having to have the eye drops that dilate my pupils. Which it should, because if you've got dilated pupils, you can't drive, and we don't all live on easy bus routes to the John Radcliffe. And so, I took it upon

myself to ring the hospital the morning of my appointment and asked whether I would be having drops to dilate my pupils? Because if I am, I need to find another way of getting to Oxford from where I live. And some chap said, "Oh, no, no, we won't be doing that." Well, guess what? They did give me the drops. They dilated my pupils, but by that time I'd driven there. I mean, it was a nightmare.

My appointment was [in the afternoon] and you have to arrive early because the traffic to Oxford and the parking is just diabolical. I think everybody in the world knows that by now! I only waited a few minutes before the nurse called my name and I went through for some tests on my eyes and that's when I discovered I was going to have them dilated. And she said that I had to have the dilation otherwise they couldn't do the test and I'd have to go home. Well, actually it turned out that that was incorrect...So that was a learning issue, and that's fine. You know, I don't object to that. We all do things like that when we're new to a job, simply because we don't know the processes and procedures, so that's fine.

So, I can't really fault the nursing or the doctor's side of it, but the admin is atrocious. I did feed back through PALS that I thought it was appalling because it was just a complete overload. It wasn't the staff on duty's fault, it was the fault of whoever arranged the appointments in the first place, if you follow. But I then had to go and sit in the main hospital and wait until I felt that I was safe to drive. Now, if I'd had an accident, I think my insurance would have been void. I was really, really unhappy about that and I remain really unhappy about that because every letter I've had since, none of them tell you that they're going to dilate your pupils and OK, once you've done it once, you know. But people sometimes don't remember these things. I just think it's almost negligent that they're not giving you this vital information.

The other thing that I found really annoying more than anything else is they say in all their admin letters that the parking is pay and display. It isn't. Fortunately, I know the JR (John Radcliffe hospital), so it doesn't surprise me but not everybody knows... They haven't been pay-and-display for quite a long time... And they also say that you can get to the [hospital] using the S2 bus from the Botley Road Park and Ride, but you can't. It hasn't gone from there since January 2023. But they don't change their literature! It is the admin side of it. It's not the clinical side of it. I don't know whether they don't have time, don't care, can't be bothered. I just think it's absolutely awful.

Q. How did you feel about the quality of the services you used?

Going off the surgery I had and then the post-op assessment... the doctors and the nurses are all brilliant and the consultant was fabulous. That side of it, I think is really good in the hospital.

I received an invitation to a pre-op assessment and there was a standard letter attached to it, which is fine, you know, but I didn't think about it. I just sent it to print and attached to it was a booklet on cataract operations - but I wasn't having a cataract operation and printed it unnecessarily. My issue was it was a 24-page booklet that I didn't actually need and when I rang and asked them about it, they said, "Oh, we send that to everybody regardless of what operation they're having." And I'm thinking, why?

The other thing I wanted to say really was when I went for my post-op assessment, [a senior consultant] mentioned that they sent a letter to my GP. But I haven't seen any letter and when I looked on the NHS App, there were in fact three letters that I was missing, and when I raised it I was told that they were sent to the GP and that the hospital expected the GP to send a copy on to the patient. That doesn't happen... But I was a bit sort of off put by that because I then had to find somebody who could give me copies of the letter, which isn't

ideal to have to go scrambling through the NHS app to find the information that should come through the letterbox, and it's actually not that easy to print from the app either.

Q. And how did you feel about the communication about your eye condition and treatment?

Absolutely dreadful... I would say that the pre-op assessment was pretty good, but for people like me I'm absolutely petrified of anyone going anywhere near my eyes and it would have been really helpful if they'd said things like, "You won't actually be able to see anything, it's all blurry...." Do you know what I mean? Because you as the patient never having had anything like this before, I'm imagining that I'm going to be able to see everything that's going on, which actually fills me with total horror. But in actual fact, you can't, because it's all blurred and stuff. It would have been useful at the pre-op assessment to have had a little bit more information about what's going to happen.

Q. Does your eye condition affect you day-to-day and do you receive any support to help you?

I don't receive any support. They do say that after two months you should get your eyes tested because your vision will have changed. And because I wanted to talk to the optician about the diagnosis, I went to a different optician to get a second opinion... on whether that optician should have known I didn't have AMD but realised what I actually did have... But it appears he should have done another test and then he would have known.

I wasn't sure whether two months is an average time or the longest time. I think maybe just a little bit more information about that and also what you can expect afterwards would have been useful... So, we're back to the communication again but I can't fault the care, they really were good.

Q. What would you like the people who make decisions about health and care in Oxfordshire to know about your experience? What changes would you like to see?

I would like to see much tighter admin... They're badly formatted, the grammar and the spelling are dreadful. Some of it doesn't even make sense. It includes many abbreviations for the medical staff, but if you're actually addressing the letters to the patient, those need to be explained. And it's around appropriate attachments and making sure that those attachments are reviewed on a regular basis, like the bus information, you know the buses and the parking and all of this stuff, making sure that what is sent out is consistent and accurate and up to date and relevant.

At one stage I had three appointments at the eye hospital and two of them were cancelled. I can't tell you the number of letters I had about that, and it's such a waste of time and money and paper. I mean, if the NHS wants to save money, that is an ideal area to do it. It isn't limited to the Eye Hospital it is throughout the trust, I think it's absolutely atrocious. I mean, one of the cancer related letters, I think I had about 10 communications for one appointment. You know and I'm supposed to get them via e-mail and they're sending them out by text, by email, by letter.

Interview 3. Experience of cataract surgery at a private clinic

Q. What concerns or problems did you have with your eyes or eyesight? What did you do / where did you get help?

Well, first thing is, I mean, [a consultant] did my cataracts in June of last year. And because I was determined that I would have a general anaesthetic, which I knew I had no way of guaranteeing that and probably wouldn't get it at all if I

went on the NHS. So, I dug into savings and went to [a private clinic]. And he did both sides, two weeks apart and it was all a very, very positive experience and I had two lovely anaesthetists. So digging into my savings was money well spent. And I'd heard horrible tales about people having their cataracts on the NHS. So, I thought, you know, I'm not doing that. And as one of my friends said, "Well, this is rainy day time, isn't it?"

Q. How do you feel about the eye care appointments that you had?

It was fine. I mean I was greeted by a lady who is a clinical service manager and because I've got a foot and ankle problem this lady greeted me at The Manor [private clinic]... because I was pushed in a wheelchair because my left foot and ankle is very wobbly and she just looked after me.

So, I went to outpatient, and [the consultant] was a bit late. But I mean, you know, I thought, 'He's a busy person, he does [NHS work too] and goodness knows what else, but he saw me for the assessment. And he said, "Right, now I'll take you to see [my] secretary." I was accompanied by somebody who has left Oxford, you know, but who is a trained nurse and I was glad she was with me because [the consultant's] secretary was going to book the [surgery] one week apart, and this lady interjected and she said, "Excuse me, but I don't really think it's a good idea for this elderly lady to have a general anaesthetic just a week apart." So it was a good thing that she was there because I thought to myself that I wouldn't have thought about that, but luckily she interjected.

Q. How did you feel about the quality of the services you used?

It was it was nice because I mean, my goodness, the nurses, they're running helter-skelter up there. And from what I hear from this lady with whom I've become very great friends, they are just run ragged up there because so many people are going there, not only through private insurance but because a lot of people are doing what I did and paying out of their savings because of the long

waits on the NHS. And you know, I think I did the right thing in using my savings to get my cataracts done the way did. It was the right thing for me to do. And yeah, you know, it's the right thing for me to do. And the anaesthetist on each occasion, the first time, it was a lovely, a jolly chap who was a bit jokey and he was very nice.

Q. What would you like the people who make decisions about health and care in Oxfordshire to know about your experience? What changes would you like to see?

To address the waiting times and quality of care and admin for NHS patients. This is why I paid out of my savings for peace of mind.

Interview 4. Experiences of multiple eye care interactions at the John Radcliffe Hospital

Q. What concerns or problems did you have with your eyes or eyesight? What did you do / where did you get help?

I've got multiple problems with my eyes, so I've obviously consulted on multiple occasions... I've had bilateral corneal transplants and I've had cataract operations in both eyes, and I go to ophthalmology and optometry at the JR (John Radcliffe), at the Eye Hospital, and I find them absolutely amazing, particularly the optometrist... If I've got a problem, I can e-mail her - for example, two weeks ago I realised I had a blood vessel in my left eye that was bulging, and she told me to come in the next day at the end of children's clinic. I mean, she's just amazing and if she thinks it's something urgent then she will just take my file and pop me

through to ophthalmology and put me at the end of their clinic list.

Phenomenal.

At other times, if I've had an emergency, I've rang up eye A&E at the JR (John Radcliffe) and you get triaged on the phone and then told to come in for an appointment. I mean you nearly die waiting because the doctors are so overworked. They're all in surgery in the morning or clinic and then as soon as they finish, they come over to eye A&E. But of course, the problem is sometimes they're delayed because the clinics are packed or surgery's taking longer than expected so you can sit in there for over three hours. And I find that very difficult because once I've taken my contact lenses out – because I'm partially sighted, I'm also deaf – so it means that if somebody tries to come and call me – I've now got hearing aids which helps but if someone calls my name I can't lip read, and I know it sounds a bit stupid, but I can't hear as much when I can't see. And I just sit there, and I can't read, I can't put earbuds in to listen to anything because then I won't hear my name being called. So, I just sit and sit and sit and it's incredibly crowded.

I'm not sure if you're familiar with the eye hospital at the JR (John Radcliffe) but the layout is confusing. It works for optometry because you get called directly off that atrium into optometry but if you're going to ophthalmology or eye A&E, once you get called through into the inner sanctums it's incredibly crowded. And very, very claustrophobic. It's so tight and it gets packed and sometimes there's not even a chair. It can be really difficult. Now, that's not the fault of any of the staff at all because they're often running around and they're working so hard. It is

simply the geography of the building, and I don't know what they can do about that, but that's my main problem.

Another level of care was last year when I had CMV (choroidal neovascularisation) in the back of my right eye, which gives you the same sort of symptoms as macular degeneration. So, I attend the macular clinic and I've had two injections in the back of my eye and that was all done very promptly. And now the optometrist, who also works in the AMD clinic, has now got me going for check-ups at the Wantage hospital, which is fantastic because it takes all that pressure off of trying to get into Oxford and the parking. In Wantage, you can park easily in local residential roads and it's just really easy. Inside there is huge waiting space and it's very organised. You get seen promptly and it and it all works so well. I think what they're trying to do is offload a few people from the Eye Hospital in Oxford into these sorts of local centres. You still see people from the Eye Hospital, for example the person who does the scan of your eye, the doctor etc... they're all from the JR (John Radcliffe). They all know [my consultant] and other people I see up there, but it just gets you out of that pressured situation at the Eye Hospital and that works extremely well for me.

The other thing I've done in the past is when I've got the symptoms of CMV, rather than go to my GP, I go to certain participating opticians (a scheme) and I went to [an] eye centre and there's a fantastic optometrist there and it was he who I first went to him when I needed reading glasses. Trouble is he's not there every day, so if you're lucky you hit the day when he's there. Anyway, he saw me immediately and he said

"No, you need to go to the Eye Hospital with this, I think you might have macular degeneration." So, he was spot on with that possible diagnosis and made me go to the Eye Hospital and did a referral.

But recently I've got this large blood vessel in my left eye and thought 'what on earth is that?' So, I thought I'd try going to a local optician. Well, the first one I went to said that they couldn't give me an appointment for two weeks. Well things degenerate very fast with eyes, and I said, "Well, that's absolutely useless. Why are you one of these participating opticians?" You know, the whole point is that you see somebody quickly and then make a professional decision about whether this person needs to go to the hospital or it's something you can deal with, you know.

And so, I then rang another one and I spoke to a lady on the desk, and they said I could go in the same day, but she came back to me having spoken to the optometrist who said it's probably because your lens isn't fitting right... and I thought to myself, 'you haven't even seen me!' So, I don't think this this sort of scheme works, it's almost like the GP option locally where GPs don't want deal with eyes because they haven't got slit lamps. So, I don't think that's working very well because the opticians need to offer an immediate, same day or next day appointment because of the way eye conditions can deteriorate and they need to not make assumptions before they've even seen the patient.

Q. How do you feel about the eye care appointments that you had?

Apart from trying to get one with local opticians, totally brilliant. When you get to see somebody, they're all fantastic, they really are very professional, very caring and always sort you out. I'm on the cusp of not

being able to drive and get tested twice a year minimum to make sure I'm OK. DVLA know about it, and I mean, if I didn't have that independence, it would really interfere with all sorts of things. You know, I'm an artist, so, you know, I go to groups, and that's often a little way away. And I couldn't get there on the bus and couldn't carry all my gear and stuff.

Q. How did you feel about the quality of the services you used?

As I say, apart from the fact that you always wait for ages in ophthalmology in Oxford and that is terrible. Optometrist okay, you don't seem to wait as long there but the waiting is just phenomenal, but it is literally that they are overwhelmed with patients. I mean, they're all working their butts off, and the doctors are fantastic. They'll come out to get a patient and discover they're in a wheelchair and they'll be really caring you know, push them in and make sure they don't bump them and all the rest of it, you know, I watch them doing it and they're all absolutely lovely and give people the time they need and deserve but they're just overwhelmed.

I find them [NHS hospital] absolutely amazing, particularly the optometrist. If I've got a problem, I can email her. For example, two weeks ago I realised I had a blood vessel in my left eye that was bulging, and she told me to come in the next day at the end of children's clinic. I mean, she's just amazing and if she thinks it's something urgent then she will just take my file and pop me through to ophthalmology and put me at the end of their clinic list. Phenomenal.

Q. Did you feel they sort of communicated everything with you effectively?

They always tell you what they're going to do and things like that. I mean, it was hilarious when I had the second eye injection, you go into like an operating theatre, they're all gowned and then the nurse puts drops in your eye, and then this doctor came in and of course I've got my lenses out, so I can't see it. I just realised it's a bloke that's about it, but he's also there with a woman behind him who wasn't gowned up and I can hear him discussing my case. And then he comes to me, and he says, well, what did you think of the doctor who did your last eye section. So, I said 'fine', you know, 'no problem'. I thought that's a bit of a strange thing to ask and then then the penny dropped, and I said, "it was you wasn't it?!" and it was. Nice humour.

He then proceeded and I could see the needle hovering above my eye. You've got your eyes fully open with the metal thingy and he's explaining to this woman exactly what he's going to do and why you don't put the needle there because it'll do this...and why you should aim it there...! This went on for over four minutes and I'm thinking gosh just get it over with! There are some things you'd rather not hear! Anyway, then he finally sticks the needle in and I went 'ouch'!, He said 'what's the matter? That's not supposed to hurt?' and I said 'well, I think you've been talking for so long that the anaesthetics worn off! 'Yeah, gosh' he said, pulling the needle out and got me some more anaesthetic! I have no idea whether he picked me for this student to see because I'm usually very calm or

whether he it was just random at all, but I thought it was absolutely hilarious, you know.

I probably know more than most about what happens, and they do explain things very well. They do explain the procedures – [the consultant] is fantastic and shows me all the scans they do of my eye. So, I've seen what the hole is like at the back of my retina. She shows me all that and shows me where the scar is, where it's closed up and I'm made very aware of what's happening and why.

Q. Does your eye condition affect you day-to-day and do you receive any support that you know to help you?

I mean, I've kind of worked it out for myself. I suppose [my consultant] has done me a pair of glasses with correction in one eye because she can't correct both eyes because my brain wouldn't cope with it. It will only cope with lenses straight on the cornea, but those glasses really help, but I mean in my own home, I can run it well. I don't run up and downstairs and things, but you know, I can get up and down stairs safely because I know the interval of the threads and all the rest of it and I can manage perfectly.

Put me in another situation and that's another story. On holiday we had a very old cottage in Yorkshire, and it had a sort of twisting staircase with uneven steps, dark red carpet which is just like, it just looked like a helter-skelter. The whole place was very dark, and I really struggled there. But on a day-to-day basis, I mean when I haven't got my lenses in, I can read with my left eye with whatever it is very close up. I mean, I don't do it

much because it causes eye strain, but I can manage in that way, but I use audiobooks.

I would make a one point. You know what, when you manage stuff, you don't even realise you're doing it. There are just things that I don't do when I haven't got my lenses in. I mean, fortunately, I've got a husband and he's got eyes when I haven't got my eyes!

I would reach out if I needed help. I mean, there's information available at the hospital, but I just don't feel I need it at the moment.

Q. What would you like the people who make decisions about health and care in Oxfordshire to know about your experience? What changes would you like to see?

Wow. But it's impossible really but it would be about reducing waiting times. Not to get an appointment, but when you're actually there not to have to sit around for three hours, you know that would be great. But I'm not sure that's feasible. And it's not in any way due to staff not getting on with the job. There's just an awful lot of us needing eye care in Oxfordshire. I mean, there's no improvement I would make to optometry – they're just amazing but I think this this local service needs sorting. I can't be the only person who's having trouble there. You know when you ring the GP and say “Ooh look, I've got this or that” and they say “Oh we don't deal with that...go to an optician...there are these are the participating opticians...”. And then you go to one of them and they can't see you for two weeks or something like that. That's not acceptable.

Interview 5. Contrasting experiences of private and NHS eye care

The opticians have been absolutely brilliant, but I've had terrible issues with my second cataract, which I really wasn't happy with at all, and I had a lot of problems. I went to the opticians and they more or less fobbed me off but it's fine now. So, it was like really watery and I had a lot of floaters and pain, but it's sorted now though.

In contrast, my first cataract experience was absolutely fantastic and that was done at the JR (John Radcliffe). But for my second one, they sent me to a private place in Banbury, maybe the Churchill? And if that had been my first time, it would have put me off! There is absolutely no communication at all. In fact, my biggest suggestion to the powers that be, is that there needs to be more communication from the surgeons to the patients because the chap in Oxford was fantastic in comparison. The consultant at the JR (John Radcliffe) went through everything with me, step by step and fully explained. However, the second time, the consultant literally only introduced herself and checked my number, that was it, basically.

And it was a different type of procedure that she did. I think it was laser and during the procedure, which she didn't explain to me, she just stuck this thing in my face which was scary. She didn't tell me it was going on or explain what would happen. Anyway, I felt something in my eye, something quick in my eye. And when I said something about it, her manner was as if I was lying! You know, I mean, I said that I can feel something prick in my eye, it's my eye and I know what I can feel! No empathy whatsoever.

Definitely more communication is needed, but like I said, not all cases are like that because my experience at the JR (John Radcliffe) was very different, and the consultant and surgeon there was absolutely fantastic.

6 Other useful resources

RNIB, 2023, 'The Eye Care Support Pathway' report, available here:

<https://www.rnib.org.uk/your-eyes/the-eye-care-support-pathway/>

MyVision Oxfordshire – local charity supporting people with a visual impairment: www.myvision.org.uk/

National Eye Health Week (NEHW) will take place from 23–29 September 2024: www.visionmatters.org.uk/

NHS information on free eye tests and optical vouchers (www.nhs.uk/nhs-services/opticians/free-nhs-eye-tests-and-optical-vouchers/)

Oxfordshire Local Optometric Committee: oxfordshireloc.org.uk/

Primary Eyecare – provides NHS-funded eye care services through local optometry practices (<https://primaryeyecare.co.uk>)

SeeAbility – eye health promotion for autistic people and people with a learning disability: www.seeability.org/

Special schools eye care service – NHS service due to end in March 2024: www.england.nhs.uk/primary-care/eye-health/optometry-commissioning/special-schools-eye-care-service/

Visual Impairment team at Oxfordshire County Council: www.oxfordshire.gov.uk/residents/social-and-health-care/disability-and-sensory-loss/sensory-impairment

Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board
(BOB ICB) Primary Care Strategy

<https://www.bucksoxonberksw.icb.nhs.uk/our-strategies-and-plans/primary-care-strategy/>

Eye care outpatient clinics provided by Oxford University Hospitals NHS
Trust <https://www.ouh.nhs.uk/eye-hospital/departments/outpatients/>