

## What we're hearing about

### Eye care

August 2021

People have increasingly been telling us about their experiences of seeking treatment for problems with their eyes and how different health services integrate. This report is designed to highlight the difficulties that people have shared in receiving care for their eye conditions.

Whilst we have heard of positive experiences:

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*"[The high street opticians were] very helpful. My husband had considerable pain in one eye at the beginning of COVID and the optician there couldn't actually examine the eye, but he spoke to him on the phone and he recommended phoning [a specialist eye] hospital and they arranged for him to go straight to [our local] A&E. There were 3 people in A&E. He had an MRI and CT within about 2 hours – he thought he had better service than usual. 144129, April 2021*

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*"I had a cataract operation a few months ago which went really well and in and out the same day and this was a referral from [a high street optician]." 145545, August 2021*

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Most people's pathways of care have been more problematic. One thing that people have told us is how during the pandemic they have not been able to access care:

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*"Each year I have an annual eye check at hospital but during the pandemic it was missed so I took myself to [a high street optician] for peace of mind." 145545, August 2021*

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*"My eyes keep getting infected. I am buying over counter medication but it just comes back. I've got an optician appointment coming up to see what is wrong. Usually, I have regular eye health appointment at [my local hospital] as part of my monitoring for Pituitary Gland brain tumour. I worry that the infections are related... I've called*

*Ophthalmology and was told to wait with no further appointments made or letters sent or follow-up calls.” 135910, December 2020*

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*“All my eye hospital appointments were stopped due to Covid because they decided my condition no longer needed monitoring every 6 months. After having 6 monthly appointments for over 10 years, that was unsettling. They informed me by sending me a letter saying that they’d reviewed my last scans and it all looked stable. I think I’d have probably preferred an appointment where they actually explained it to me.” 145077, June 2021*

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People have also expressed their concerns over delays and waiting times for treatment:

*“I have an eye condition called Keratoconus and had a cornea transplant when I was 18. In the last 6 months, I felt a decline in my eyesight so went to [a high street optician] and was referred to [my local] hospital, however, the wait [for an appointment] felt too long so I decided to get someone to drive me to A&E a few days later. Here, the consultant said I needed to see a specialist. There, I was given antibiotics (oral and IV). I had an infection that had punctured my cornea. I’ve been off for 5 weeks from work and my eyesight is slowly coming back... I feel if I had waited for my appointment, my eye condition was so serious I could have been left blind. As it is I am worried now I may need a further Cornea transplant sooner rather than later. I should have been advised to go to A&E.” 145540, August 2021*

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*“...I live on a pension and have no private medical insurance, but I was so worried about the potential damage being done by the delay that I dipped into my savings and by contacting private hospitals in my stressed and exhausted state, I was able to see a consultant ophthalmologist... To my great relief, he was able to reassure me that my symptoms were caused by something called Posterior Vitreous Detachment, and that no surgery would be needed...How is it possible that a condition which all the experts (and my own research) agree merits investigation within 24 hours can take this hospital more than six days to schedule?... Would YOU be happy to wait six days if you feared losing your eyesight and were told in A&E that you need to be seen within one day?” 132789, April 2021<sup>1</sup>*

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People have also shared their experiences of the impact it has on them when services don’t integrate well and they have to pursue care:

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<sup>1</sup> Response from provider: “The patient submitted a formal complaint to the Trust which has been responded to already. We have put in place some new processes to address the concerns raised by the complainant.”

*A lady saw a GP in approximately February or March 2020. One of the issues she asked about was a problem she was having with her eyelid. The doctor didn't look at it but told her it was probably a blocked eyelash. The problem got worse, and she returned in mid-March but was told it was nothing to worry about. During lockdown the situation got worse, she went again, and this time saw a practice nurse. She also had a subsequent video appointment with a GP as it was now hurting and bleeding.*

*In early July, she went to a pharmacist as the situation was getting worse. The pharmacist suggested she seek assistance from an optician straightway. The client consulted [a private] optician as this was urgent, the optician thought the problem was cancerous and should have it seen to as soon as possible. She has been to hospital and has been diagnosed with a basal cell carcinoma which will require significant surgery.*

*She therefore wishes to complain about the standard of care she has received. She felt a little intimidated by the doctor so did not want to speak to them directly. **123466, July 2020***

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*I am a student [in Surrey] and I've had a problem with my eye since Oct 2019. It began when my eye had become red and painful and I thought I might have conjunctivitis... I went to the pharmacist and was given eye drops and told to go to GP if it didn't clear up or was getting worse. It got worse and so contacted the GP. Called the surgery and they said they can't help, and I should go to an Optician. I went to [a high street optician]. Optician felt it was a cut or I had damaged it somehow rather than conjunctivitis. They referred me to the eye clinic at [the local hospital]. I didn't hear anything further from the eye department. After another 5 days and still using drops, I called 111, who advised me to go to A&E. I explained at A&E everything that had happened, and that the Optician had sent in a referral to the eye department. I didn't feel listened to, I was given a gel and was assured it would clear up. I always feel that visiting A&E as a young person there is a lack of attention, seems better when there is an 'adult' with you.*

*I [returned to my home town outside Surrey and got an appointment at an eye clinic]. I saw the consultant, I left with strong antibiotics and a letter to [the Surrey hospital] which I was advised to give to my GP. The letter said I needed to be seen within 7 days by the eye department. I heard nothing further and my eye was still getting worse. I contacted my GP to chase referral and complain I hadn't heard anything, and that I needed to be seen within 7 days. By this time my eye looked and felt terrible, so painful that [we drove] to [a specialist] eye hospital, who also thought the infection was viral and upped the dose of my antibiotics. By this point I had been given drops, gel, tablets, steroid drops and antibiotics. The eye department [in Surrey] did get in contact but by this point I had transferred my care to [the specialist hospital]. My eye was still not getting better and so I went to a specialist A&E (Eye specific). Luckily there happened to be a specialist there who spotted the parasite and confirmed I had been misdiagnosed. I am now under their care. I am going to have a cornea transplant. I fund myself and have two jobs as well as being in full time education. I have been unable to work for four months and I am currently unable to drive. Going through all this I felt dismissed... I felt*

*that travelling between healthcare has complicated things, but I didn't know what else to do. The Optician spotted this way back in October but there has been a lack of attention. I have since changed my GP surgery as I felt they didn't help at all."* **113921, February 2020**

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*"...No matter how I begged, I was told that there was no help to be had – I even contacted my GP in the hope that they could prevail, but there was no budging the eye hospital. I met with a wall of apathy. When I expressed my extreme concern at the delay, the eye clinic did suggest I contact an optician, but when I did so the optician said that his only recourse would be to also refer me to the Eye Clinic. He stressed the need for me to be seen urgently and confirmed that my symptoms represented an eye care emergency."* **132789, April 2021**

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*"In January 2019 after a routine check-up at [a high street optician], it was advised that I seek medical attention and get a test for a condition called Keratoconus. The [optician] had written down the suspected condition and advised me to show it to the Consultant so I could be tested for it. None of my symptoms were corrected with lenses that we tried. As a result, I was referred for an MRI scan which came back negative for any brain conditions and visible eye conditions. I was then referred to see an eye specialist where I saw numerous Consultants and I was dismissed of Keratoconus without being tested for the condition. One of the consultants I saw referred me to [a specialist eye] Hospital where I had a test for the back of my eye (Keratoconus affects the front Cornea) where they diagnosed me with Macular Degeneration in my right eye and said my left eye was completely normal. After suffering with severe anxiety after not being tested for what I suggested numerous times, and my eyesight deteriorating and causing me pain, knowing my symptoms were clear signs of Keratoconus as stated by the [optician]- who I did re visit and told him what I had been diagnosed with. He was appalled that they hadn't tested me for Keratoconus and wrote it down again for me and told me to continue to ask to be tested for this. Following this advice and my current emotional state, I was calling the eye department numerous times daily and getting passed to different secretaries and still not getting anywhere. Finally, after months of consistent calling I received a date for the test of Keratoconus which came back positive. A month after being diagnosed with Keratoconus I received an appointment with the Lead Consultant in November 2019, who was very apologetic for how I had been previously treated. He said: 'I wish I had seen you sooner.'*

*As a result of waiting to get tested my eyesight has deteriorated, having had the appointment, and being operated on sooner my eyes would not be as bad as they are today. Following this appointment, he put me on the emergency list to be treated and operated on. I underwent my first operation on my right eye in December 2019 and then my left eye in February 2020. I now have to wear special contact lenses that push my cornea back to help improve my vision. I will never fully be cured of this condition and now receive private care. To conclude, I never thought I would be writing a complaint against the NHS as I have received a lot of care for other conditions but I feel I have not only suffered physically with my eye sight but also mentally, as I was dealing with this for*

*a year without getting anywhere knowing that my eye sight was deteriorating. I feel I have been let down by the NHS as they didn't provide me with the care I needed. I was incorrectly diagnosed, and my symptoms were ignored, as I believe if the [optician] can pick up these symptoms then the eye consultants I saw should have picked this up sooner." **125001, August 2020***

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