

Please see below my recent experience with eye screening. This has happened since I moved area.

Positives:

- Quick referral into a new regions eye screening programme from my new GP
- The new location for screening was actually in my GP. This made the experience not only easier to access but less intimidating attending at a practice rather than a local acute
- Like that I can see results / GP communications on the NHS app regarding my screening

Negative:

- Conflicting patient / GP communications from the programme: After attending my first eye screening in HNY I received an alarming letter to my home address that stated I had Diabetic Maculopathy and needed referring for further testing using specialist equipment. The letter stated it was important I attended this appointment to protect my eyesight. This was extremely distressing, I was aware I had background retinopathy and had been managing my sugars extremely well so ended up having a health scare spiral due to feeling helpless and like my efforts hadn't made any difference.
- I fortunately had a T1D GP in person review a few days later. I was expecting my GP to bring it up as a topic of conversation but when they didn't I expressed my worries and concerns. The GP was shocked, they said they'd seen my eye results and that it wasn't anything they were worried about.
- They showed me the letter that the GP had received (separate to what a patient is sent) that outlines exactly 'This patient does not require a referral to ophthalmology for Diabetic retinopathy or maculopathy, however we will be following them up in our digital surveillance clinic.'
- I have however received a further referral appoint for next week.

What I am trying to emphasis about this situation is the conflicting messages, poor use of language and general patient communication failures. This poses issues for patients such as concerns on clarity and accuracy, unnecessary fear and anxiety and loss of trust in the system.

This could discourage someone for attending any future appointments. The way in which patients are communicated to needs to be considered more. I don't see why patients and GPs receive separate correspondence. Had I received the letter my GP had I would not have had such a serious health spiral.

I've had quite bad experiences before, only twice (but that was enough to impact me) where because they do eye screenings for type 1s and type 2s I've been generalised to being type 2 and been told wrong information, for example not being able to eat cake, that I shouldn't be doing what my friends do because of my health etc, and me trying to tell them I can as long as I inject and everything is in moderation with a balanced diet as I'm type 1 diabetic. There has been limited consideration to the difference which was hard! But in the most recent couples years I haven't had this issue again and have had no issues with lovely people

I've always had mixed feelings towards the eye screening programme. Whilst we are really lucky to have access to the service monitoring us annually, the appointment letter always feels to me like another reminder of a major possible complication. When I was 21 after years of always having clear screenings, I was sent a letter in the post saying background retinopathy had been seen in one of my eyes. Because I received this on a Friday evening, I spent the whole weekend thinking I was at risk of going blind despite working hard at my diabetes management and meeting the targets my clinic team had been setting. Thankfully, the screening staff were really helpful when I was able to contact them on the following Monday, explained exactly what had been seen, and also acknowledged the fact that these standard letters usually cause this type of worry as they deliver potentially life changing news without warning and also have set standard paragraphs that don't appreciate the gradation of eye complications. In this case, a background retinopathy letter was sent to me as a potential single microaneurysm was seen (that ended up actually not being there at my next screening) but someone with multiple haemorrhages and extensive damage would have received the same letter.

To me, this is a symptom of the wider problem - that diabetes and its care is so individual to a person that this type of "one size fits all" really backfires, having had multiple friends experience something similar. I also think that receiving such worrying news through the post and not being able to seek more information immediately, rather than talking it through is a sign of how overstretched and underfunded service and information provision in the screening services are.

Finally, I think how we discuss complications with young people, especially vision-related, could be considered more carefully. I was always told that meeting my targets would minimise my risk of any complications, but the reality is that the unexpected happens even with the best of efforts. Removing the shame around complications that can occur inevitably from having diabetes for a long period of time or for so many other reasons would probably help set us up to be more prepared when things like this do happen. I think this would also help us truly view the screenings as a chance to deal with something early rather than another reminder that you aren't doing well enough.

The waiting room at those appointments is always the same. I'm always the youngest there by at least 50 years. They all turn round and look at me wondering what I'm doing there. That can be quite off putting. I've always had positive experiences actually in the appointment themselves- staff polite, friendly and clear in setting my expectations. Eye drops obviously aren't pleasant but I understand they are needed.

Initially, I didn't have a great experience with my eye screening. No fault of the staff at all, just the eyedrops which I absolutely hated. But for the last couple of times I've been OK with them and I think that has to do with me finding a way to be OK with it because I'll always need to have my eyes screened. I found the best way for me was to pack my earbuds, put one in so I can still hear my name being called out and watching something on YouTube to distract from the eyedrops and it works a treat, apart from the fact I can slowly see my vision getting more and more blurred as I'm watching my phone but that doesn't matter because its now just another thing I can get in and get done without any worry.

My experience with the diabetic eye screening has been positive. It's easy to make or change an appointment to what best suits me. I've never had a long wait time once I get to the appointment and the staff are always super friendly. The only issue I've had is when they send you the letter with your result, I had one that told me there were some changes. This really freaked me out and panicked me because nothing was explained to me. But luckily I had an eye test at the opticians a couple days later where they explained it to me.

My screenings are always really good. All the staff are really polite and I get the results quickly. It kinda hurts but there's nothing new about that as most things we do cause we have diabetes are painful.

I have always had good experiences with diabetic eye screening - the staff are always lovely and the mobile screening vans make the appointments super quick and convenient! I find that the people screening usually are very reassuring and will give me an indication that things look okay on the day which really helps ease anxiety when waiting for results.

Good, organised by primary care so efficient (unlike hospital based care), runs on time and combined with foot screening. Results letter within a week. But I'm low risk so may well be different experience for others in my area.

I've always had a good experience with getting my eyes screened every year, luckily I've never had any problems with my eyes. One time I did have the optician show me another diabetic patients eye screening where they had a lot of complications and used it as a way of saying 'look after yourself or this will happen to you' which put things into perspective about good diabetes management but it was a bit uncomfortable to see.

Hi! My experience of having my eyes screened has been very positive so far. I've had it done at my GP rather than my hospital, and it's always been done efficiently and well, and I've had results back clearly and quickly, staff have always been friendly as well!
