# Voice of the Customer: The eye Care Pathway Part 1

**(Oct – Dec 2021)**

Insights into the lives of blind and partially sighted people in the UK and the issues that matter most to them. This time on their experiences of navigating the eye care pathway. We also asked participants on their experiences of e-scooters.

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## 

## Introduction

As the UK’s leading sight loss charity, RNIB stands side by side with blind and partially sighted people through every challenge they face. To do this properly, in a constantly changing world, we need to keep listening to our customers to better understand their lives, needs and wishes.

Our ‘Voice of the customer’ is an ongoing programme which includes a regular survey of up to 400 people with sight loss, analysis of what people are talking about on our social media channels, and monthly focus groups which allow us to dive deeper into issues.

Insights and findings from these channels and initiatives are published in a series of quarterly reports to help us – and our partners – better understand the changing needs of blind and partially sighted people.

Not only will this help us respond to new challenges as they develop, we will use this knowledge to continue our mission to break down the barriers for people with sight loss and create a world where blind and partially sighted people participate equally.

For this round we focused primarily on the eye care pathway. We also included some additional survey questions about e-scooters.

## Key insights

* **There is significant variation in experience of eye clinic care. While the vast majority are generally satisfied with the care they receive, a significant portion aren’t. A quarter are dissatisfied with information and referrals into support services. Some experience long waiting times or have difficulty booking appointments, and around half have experienced cancelled or reduced appointments due to the impact of Covid on hospitals.**
* **Early emotional support is crucial, yet too many VI people experience a lack of empathy at diagnosis. Referrals into emotional support services only happen for 1 in 5 patients, and whilst there has been some improvement in this area over the past 10 years, those being offered such support are still in the minority.**
* **E-scooters present a significant concern for people with vision impairment. Many VI people who travel in areas where e-scooters operate feel less confident on the streets or now avoid those areas. Concerns stem from the use of the vehicles in pedestrian spaces, the speed they travel at and their lack of noise making them difficult to be aware of.**

## Eye care pathway

The eye care pathway is a term sometimes used to represent the patient journey from initially experiencing eye problems to receiving appropriate diagnosis, support and care.

There is a significant variation in experience of eye clinic care for people with a vision impairment. In general, the vast majority of respondents to our survey were satisfied with the care they received from professionals in the eye clinic for their eye health or eye condition.

* **Three quarters** (78%) were satisfied with their care.
* **Three quarters** (75%) were satisfied with the overall accessibility of their eye clinic experience, which includes clinic visits and communications from the clinic.
* **62%** were satisfied with the information about, or referrals into, other support or eye care services they received.

**“I attend the macular clinic regularly and have recently had a cataract removed. The professionals take great care to explain the condition of my eyes and involve me in any decision making.”**

(Survey respondent)

However, **over 1 in 10** (13%) were dissatisfied with the care they received. With the volume of people passing through eye clinics this could **still represent a significant number of people**.

Although the statistics appear to show a positive picture of satisfaction, many people – even those who were satisfied overall – told us about poor experiences or areas for improvement. Findings from our focus groups suggest that people are generally satisfied with clinical care (such as treatments), but elements of the process (such as accessibility or referrals) and personal impact (empathy and emotional support) are often cited as needing improvement. We explore these areas for improvement in more detail in the rest of this section.

### Lack of emotional support – especially crucial at diagnosis

The offer of emotional support, especially at the time of diagnosis, is crucial, yet most of our focus group participants were not offered this until sometime after their initial diagnosis.

Some people felt a **lack of empathy** from eye care professionals who didn’t treat them as a “person”. Only **1 in 5** (21%) survey respondents were referred to any emotional support services. However, for those diagnosed in the past 1 to 9 years, the number being offered emotional support increases slightly to one third (33%) – significantly higher than the 14% offered support 20 or more years ago. This indicates there has been some improvement in referring patients with a sight loss diagnosis for emotional support over the past 10 years – yet those being offered such support are still in the minority.

**“In general, I find ophthalmologists to be a little dismissive. Not good with people. I feel like an eye specimen on legs!”**

(Survey respondent)

### Little information about a condition or referrals to support

**13%** of our survey were dissatisfied with the information they received about their eye condition and the Certification of Vision Impairment (CVI) process. Some respondents suggested the way information was provided was the issue, again highlighting a sometimes impersonal approach.

**A quarter** of survey respondents were dissatisfied with information and referrals into support services by the eye clinic. These services would include low vision centres, social services or charities providing a range of services such as emotional or practical support (such as rehabilitation or technology advice).

**“Happy with my care. But unfortunately have not been referred for any other help. Not even any leaflets or anything.”**

(Survey respondent)

Focus group participants spoke about receiving little information about their diagnosis, and little support after the initial diagnosis. They also told us that little information and emotional support was provided for their family. When they did connect with sight loss charities they gained more access to information, advice, and services, and increased their understanding of sight loss. Having access to local societies and councils helped with adaptations, technology advice and mobility training, and peer connection was also said to be​ extremely valuable. Participants told us that a checklist of available support would be helpful from the start.

### Poor accessibility and sight loss awareness

**16%** of survey respondents were dissatisfied with accessibility. This includes clinic visits as well as communications from the clinic.

Focus group participants told us about inaccessible signage in hospitals, and even when signage was accessible it was not always apparent what was being referred to (for example when jargon or acronyms are used). Participants also stressed the importance of having accessible printed information to take away, and felt that sight loss awareness training for medical staff and opticians would help.

**“Our local clinic always seems to be over booked. They also installed a television screen to tell you when it is your turn to go forward - this in an eye clinic? The least they could do is call out your name.”** (Survey respondent)

### Long waiting times – need for timely treatment and support

For some, the pathway is punctuated with long waits in-between appointments and referrals. **1 in 5** (22%) survey respondents were dissatisfied with waiting times, and a small number felt delays had caused their vision to deteriorate. In the last year, **half** of the respondents had experienced cancelled appointments or less appointments than usual because of Covid affecting hospitals. Many also spoke about difficulties making appointments.

**“I lost my sight waiting for an appointment.”** (Survey respondent)

The importance of timely treatment and support was raised in focus groups. Participants told us that timely treatment reduces the likelihood of a condition getting worse, and emotional and employment support in particular needs to be in place at the earliest stage. This is especially important given that some people wait to see if their sight will get worse before they seek advice. Participants also told us of medical professionals choosing to wait to see how a condition develops, with no help or support offered in the intervening time. The longest part of the process was said to be waiting for contact from rehab services, which when finally accessed, helped build confidence and enabled independence. Obtaining a CVI can speed up the process of accessing support, although some people experience difficulties and delays in obtaining one.

### Inconsistency and regional variations

Some focus group participants spoke of an inconsistency in the support and advice offered, citing that the Eye Clinic Liaison Officer (ECLO) service was only available in certain hospitals or on certain days.

Some survey respondents told us about difficulties with getting transport to clinics, particularly specialist or regional hub clinics that involved travelling greater distances. In addition, lengthy discussion threads on our social media channels indicate that parents and carers of VI children are struggling to understand the variabilities across the UK of the certification and registration processes for their children, the lack of, or prolonged wait for sight loss treatments, assessments, and support.

## E-scooters

E-scooters present a significant concern for people with vision

impairment, most commonly around personal safety. Anxieties stem from the use of the vehicles in pedestrian spaces, the speed they travel at and their lack of noise making them difficult to be aware of. **Over 1 in 2 people** (55%) with a vision impairment who travel in areas where e-scooters are present said their journeys had been negatively impacted by their presence.

### Less confidence when out and about

**Over 1 in 2** people (56%) with a vision impairment who travel in areas where e-scooters are present felt less confident on the streets because of them, and **a third** (35%) found themselves avoiding areas where they knew e-scooters were operating.

### Collisions

Of those who have encountered e-scooters on their journey, **1 in 6** have experienced a collision (either with a moving or standing scooter), and **almost half** (47%) had experienced a near miss. Of those who did collide with an e-scooter, **1 in 10** told us they were injured.

### Comparison with bicycles

Most respondents had similar opinions of bicycles as they did of e-scooters – the main issues for both being use on pavements, lack of sound and lack of consideration for pedestrians. In fact, slightly more people (56%) felt their journey was negatively impacted by bicycles, perhaps due to the higher volume of bicycles on the streets, and their presence in all areas of the UK.

### Towards more equitable shared spaces

The fact bicycles were of equal or greater concern for VI people suggests the proliferation of e-scooters alone is not the key driver impacting people’s confidence when using the streets. A broader understanding of how all users of pedestrian spaces impact the journeys of VI people would help define what the pain points are and start to build a picture of how people with vision impairment could be better supported to make journeys confidently.

## Key issues for the sector to tackle

* Blind and partially sighted people experience long waiting times for appointments, treatment, and referrals into further support services. This can lead to a deterioration of their sight condition and/or loss of confidence and independence.
* Eye clinics do not always incorporate best practice around accessibility, in terms of both environment and communications, and some staff lack sight loss awareness.
* Blind and partially sighted people do not receive adequate and timely levels of information about their eye condition or the sort of support that they can/should expect.
* There is no accepted definition of the sight loss pathway. Eye care professionals lack a framework on how to support beyond medical treatment, and blind and partially sighted people do not know what the minimum they should expect is.
* Some ophthalmologists do not fully appreciate the emotional impact of a sight loss diagnosis and can lack empathy in the way they deliver the news or not refer people into the emotional support services they need.
* ECLOs deliver an invaluable service to people at point of diagnosis but their provision is inconsistent across hospitals and days of the week.
* Friends and family are not supported to help people with sight loss manage their changing situation.
* Anxiety over the use of micro-mobility vehicles in pedestrian locations adversely impacts many blind and partially sighted people’s willingness and confidence to make independent journeys.

## References

All of the research in this report is drawn from our quarterly tracker survey from Oct-Dec 2021, focus groups with blind and partially sighted people carried out Oct-Dec 2021, and analysis of our social media channels during this same period. Reports produced from these sources are unpublished but summarised here.

## About RNIB’s research

RNIB is a leading source of information on sight loss and the issues affecting blind and partially sighted people. Our Research and Knowledge Hub contains key information and statistics about blind and partially sighted people including our Sight Loss Data Tool, which provides information about sight loss at a local level throughout the UK. You’ll also find research reports on a range of topics including employment, education, technology, accessibility and more. Visit our Knowledge and Research Hub at: **rnib.org.uk/research**