RETINA UK
SIGHT LOSS SURVEY 2025

Findings from our survey of over 600 people living with inherited sight loss.

June 2025

RETINA UK

WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

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We would like to thank abbVie and Sepul Bio for their support in delivering the Sight Loss Survey 2025. Our sponsors have not been involved in the design, content, review, or distribution of this survey.

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Welcome from our Chief Executive

Retina UK is the only UK charity solely dedicated to supporting people affected by inherited sight loss. Our mission is twofold: to help people living with these conditions and their families live better today, and to fund vital medical research that brings hope for treatments in the future.

We are deeply grateful to everyone who took the time to participate in the 2025 survey. Your voices are not only heard, but they are also powerful and shape the future. The lived experiences and insights you've shared are essential in driving meaningful, evidence-based change both for us, and in the broader context.

This is our third consecutive insight survey, and together, the data paints a compelling picture of the ongoing challenges faced by the inherited retinal dystrophy community. It also shows us clearly where improvements are most needed; in healthcare, finding treatments, daily life, emotional wellbeing, and access to support and technology. Most importantly, it guides how we shape our services and priorities to ensure we are meeting real, current needs.

Thank you once again for sharing your experiences. Your input strengthens our collective voice and helps us work toward a brighter future for everyone affected by inherited sight loss.

Tina Garvey
Chief Executive
Retina UK

Introduction

This is Retina UK's third comprehensive tracking survey of the experiences of people with inherited sight loss. It follows similar surveys in 2019 and 2022.

Our aim is to better understand people's views and experiences, and how these may be changing over time. We use what we learn to improve our support.

Each time the survey includes a mix of questions we have asked before, to help us understand whether anything has changed for the inherited sight loss community. We also take the opportunity to ask new questions, for example, in response to advances in assistive technology.

Each time, our questionnaire is designed to be completed by anyone living with inherited sight loss (or by their parent or guardian, if they are under 18). We test the questionnaire with people with sight loss, to check that the questions and response options are appropriate. In 2025, the questionnaire covered:

- Demographic information
- Sight loss condition
- Quality of life
- Services and support
- Mental health
- Clinical research
- Engagement with Retina UK

The questionnaire could be completed online or via a printed booklet. Print copies were distributed by post with copies of our magazine *Look Forward*, and participation promoted through Retina UK's communications channels, and via health professionals and online communities. We provided volunteer assistance to those who may otherwise have struggled to complete the questionnaire.

In total we received 614 responses.

Summary of key findings

TYPES OF SIGHT LOSS

- Most respondents (88%) are sight loss registered.
- Almost two thirds (63%) have been diagnosed with retinitis pigmentosa (RP).
- Two thirds (67%) were diagnosed over 20 years ago.
- Almost a third (29%) could name the gene or genetic disease type behind their sight loss – repeating the positive picture from 2022.
- 8% have no vision at all, and 4% have good overall vision.

QUALITY OF LIFE

- Half of respondents (53%) say their sight loss has a severe or very severe impact on their quality of life – slightly higher than in 2022.
- Three quarters (72%) say they're managing their sight loss well, compared with 24% who would like to manage it better. Those managing well include above-average proportions of those diagnosed more than 20 years ago, and people who engage with Retina UK.
- Anxiety and loss of confidence continue to be the biggest emotional or psychological impacts of sight loss, though more people reported anger than in 2022.
- Sight loss particularly impact on mobility and getting around; leisure time and hobbies; and social life. Impacts on education and work have worsened, returning to pre-Covid levels.

SERVICES AND SUPPORT

- Experiences of receiving diagnosis appear to have returned to a positive upward trend, following a dip during the pandemic.
- More people now appear to be signposted to Retina UK, and the proportion offered emotional and psychological support at diagnosis is increasing.
- Just over half of respondents attended an ophthalmology appointment in the past year. One in ten say they don't have an ophthalmologist involved in their care.
- The most useful services for people with sight loss remain: benefits advice; mobility training; access to work schemes; and social services support. There are unmet needs for support from ECLOs and social services.
- Informal support mostly comes from other national sight loss charities, and informal peer support. Satisfaction with support from Retina UK staff and volunteers has increased significantly since 2019.
- More than one in three respondents (38%) has experienced at least one fall or accident in the past five years that required outside support. The proportion who sought support outside of NHS services has increased since 2022.
- Respondents use a wide range of aids, in particular, in-built accessibility features of smartphones and tablets, and flashlights and illumination devices. Many cite expense as a barrier to accessing aids they'd like, as well as not knowing how to obtain them.

CLINICAL RESEARCH

- Just over four in 10 respondents are aware of clinical research into their sight loss, a drop from 2022 levels. But more have participated in research compared with previous surveys.
- Retina UK remains the top source of research information. As with previous surveys, awareness of research is much higher among those who have engaged with Retina UK compared with those who haven't (49% compared with 28%).

MENTAL HEALTH

- One in five respondents (19%) say they have accessed mental health support in relation to their sight loss. Of those who hadn't, 83% said it was because they were not in need of it.
- Of those who had received support, four in five (79%) had accessed a talking therapy such as counselling or psychotherapy. Two in five (44%) received prescription medication.
- While half referred themselves for support, the proportion referred by a healthcare professional increased to 40% from 33% in 2022. Respondents reported shorter waiting times, with one in four receiving treatment within two weeks of referral.
- Most benefited to some degree from their mental health support, with a small increase in the minority who said it made managing much easier, from 18% in 2022 to 22%.

ATTITUDES TO RETINA UK

- Online search continues to be the main way recently-diagnosed respondents find their way to Retina UK, though signposting from health professionals remains an important referral route.
- Three in four respondents (76%) had engaged with Retina UK in some way – similar to previous surveys.
- Engagement remains highest among those who are: sight loss registered; diagnosed more than 20 years ago; diagnosed with RP; and those who say they're managing their sight loss well.
- Most respondents agree Retina UK is approachable, trustworthy and ambitious on behalf of people with sight loss. There is broad agreement that the charity listens and responds to people with inherited sight loss.
- One in three rate Retina UK's services and support overall as 'excellent' – higher than in any previous survey.
- Satisfaction was highest with core Retina UK communications: newsletters, website and annual conference.
- More respondents than in 2022 or 2019 agreed that, thanks to Retina UK, they had more confidence in managing the challenges of sight loss, and greater awareness of available support.

About the respondents

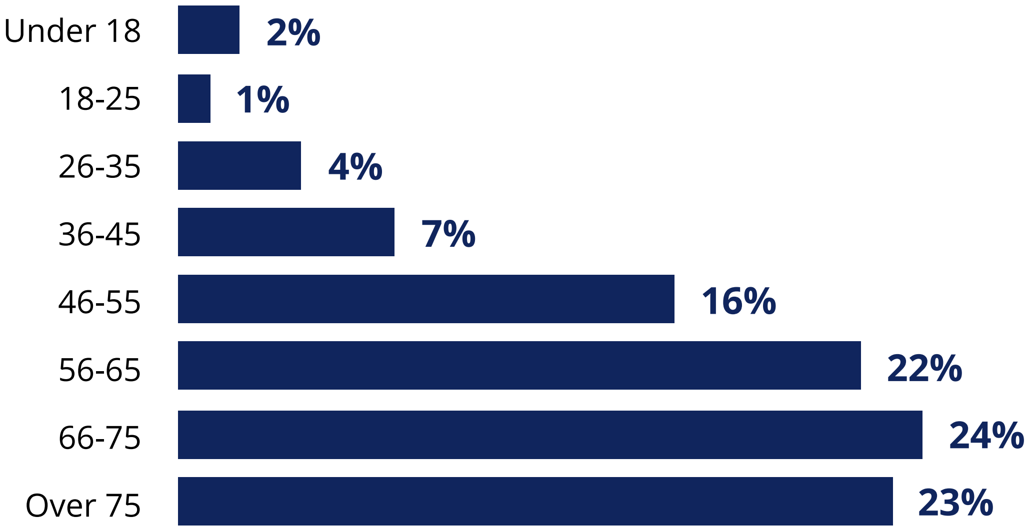
KEY FINDINGS

Of the 614 individuals who responded:

- 96% completed the survey on their own behalf and 4% were the parent/guardian responding on behalf of a child aged under 18 (same as in 2022).
- Over half identified as female (57%) and under half as male (43%).
- 95% were white, 3% were from an Asian or mixed Asian background, and the remainder were from other ethnic backgrounds.

The age range was as follows:

Chart 01: Respondent ages (all respondents)



- 55% were retired and 27% were in employment (including self-employment). One in 10 (11%) were unable to work because of their health condition or disability.

Retired	55%
Employed (full / part time / self employed)	27%
Doing voluntary work	12%
Unable to work because of a health condition or disability	11%
In full or part-time education or training	6%
Unemployed	5%
Other	8%

COMPARISON WITH PREVIOUS SURVEYS

The demographic profile of respondents was broadly similar in 2022 and 2019.

This was the first time we'd specifically asked whether people were unable to work because of a health condition or disability. An analysis of open-end responses indicated the barriers some face, including:

- Impact of sight loss on ability to find or keep work
- Loss of previously held jobs or careers, as sight loss progresses
- Lack of understanding, support or fair treatment at work

"I had to retire from work due to sight loss, not much support."

"My employer of 22 years paid me off after my diagnosis."

"I worked as an holistic therapist and doing arts and crafts, but I cannot continue because of sight loss."

Types of sight loss

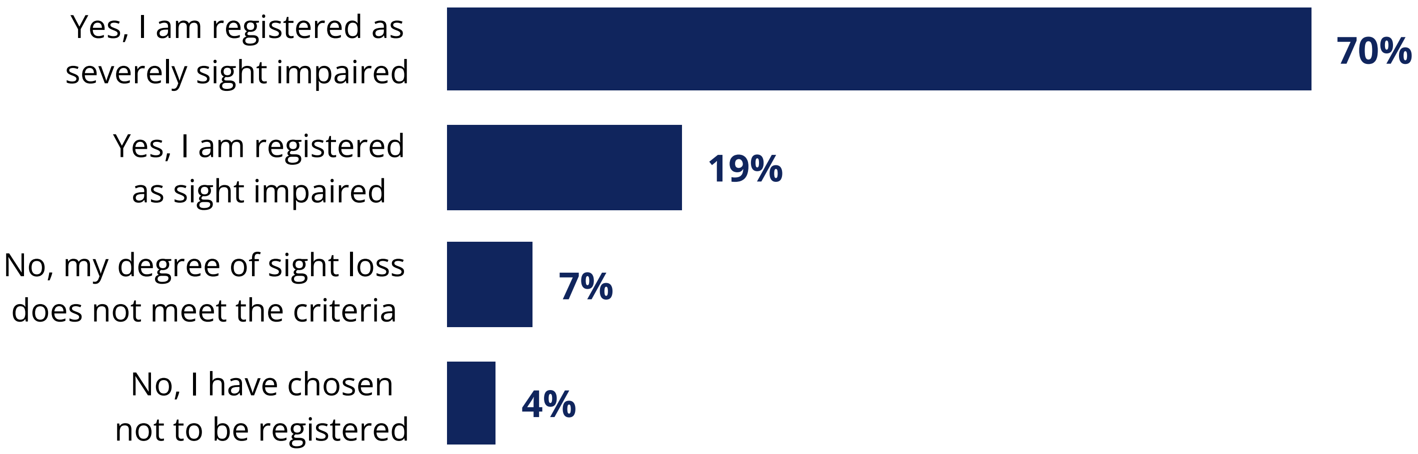
KEY FINDINGS

- Most respondents (88%) are sight loss registered.
- Almost two thirds (63%) have been diagnosed with retinitis pigmentosa (RP).
- Two thirds (67%) were diagnosed over 20 years ago.
- Almost a third (29%) could name the gene or genetic disease type behind their sight loss – repeating the positive picture from 2022.
- 8% have no vision at all, and 4% have good overall vision.

SIGHT LOSS REGISTRATION

Almost nine in 10 respondents (88%) were either registered as sight impaired (19%) or severely sight impaired (70%). Those not registered including 7% who said their degree of sight loss did not meet the criteria for registration, and 4% who have chosen not to be registered.

Chart 02: Sight loss registration (all respondents)



DIAGNOSED CONDITION

Almost two thirds of respondents (63%) had been diagnosed with retinitis pigmentosa (RP). The remaining 37% had a range of other conditions, including 2% with more than one diagnosis. The most frequently mentioned singly were Usher syndrome (7%) and Stargardt disease (3%).

Classic retinitis pigmentosa (RP)	63%
Usher syndrome	7%
Stargardt disease	3%
Cone-rod dystrophy	2%
Rod-cone dystrophy	2%
More than one condition	2%
Bardet-Biedl syndrome	2%
Choroideremia	2%
Leber congenital amaurosis	2%
Other	9%

Note: table only shows responses with 10+ counts.

GENETIC DIAGNOSIS

Over four in 10 respondents (43%) said they had received a genetic diagnosis for their sight condition. This is a slight increase on 2022 (39%).

Analysis of free text responses shows 29% of all respondents were able to provide the name of a gene, or a specific type of inherited retinal dystrophy which correlates with a specific gene.

This repeats the positive picture indicated in 2022, where 31% could name the implicated gene or genetic disease type. Since 2019 there has been a considerable increase in the proportion of respondents who were able to name their specific genetic diagnosis.

TIME SINCE DIAGNOSIS

Two thirds of respondents (67%) were diagnosed over 20 years ago:

Past 12 months	2%
1 – 5 years ago	8%
5 – 10 years ago	8%
10 – 20 years ago	15%
Over 20 years ago	67%

People who were diagnosed more than 20 years ago are much more likely to be registered as severely sight impaired (79% compared with 51%). This is similar to previous surveys.

REMAINING VISION

Respondents reported different degrees and types of remaining vision. Fewer than one in 10 (8%) had no vision at all, while 6% still had good overall vision.

No vision	8%
Light perception only (or shadows only)	15%
Some useful central vision	40%
Good central vision	26%
Some useful peripheral vision	20%
Good peripheral vision	4%
Good overall vision	4%
Other	7%

Those who used the open-ended option to describe aspects of remaining vision not captured by the tick-box responses talked about specific patterns such as tunnel vision, problems with night vision, or no side vision; differences between eyes; and environmental factors like light sensitivity.

COMPARISON WITH PREVIOUS SURVEYS

Consistency with previous results shows our inherited sight loss community has remained stable over the six years of this survey. The proportion of people who can name the gene implicated in their sight loss condition has remained at 2022 levels, but this remains a positive shift since 2019.

Quality of life

KEY FINDINGS

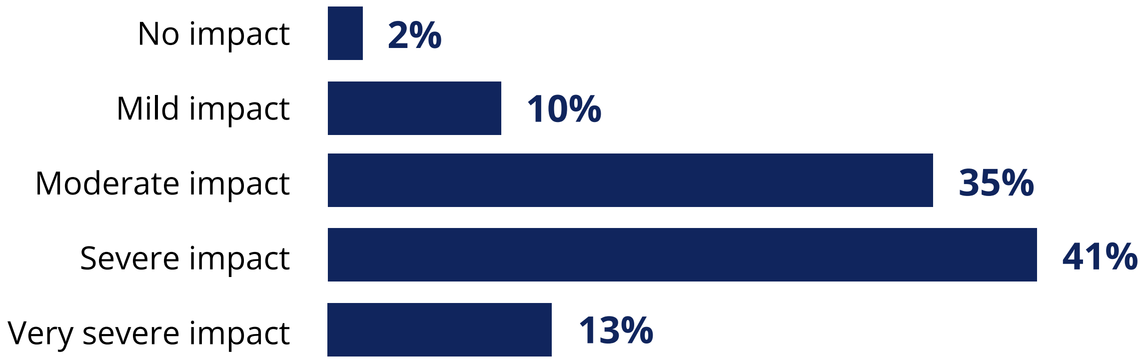
- Half of respondents (53%) say their sight loss has a severe or very severe impact on their quality of life – slightly higher than in 2022.
- Three quarters (72%) say they're managing their sight loss well, compared with 24% who would like to manage it better. Those managing well include higher proportions of people diagnosed more than 20 years ago, and people who engage with Retina UK.
- Anxiety and loss of confidence continue to be the biggest emotional or psychological impacts of sight loss, though more people reported feeling anger than in 2022.
- Sight loss particularly impact on mobility and getting around; leisure time and hobbies; and social life. Impacts on education and work have worsened to pre-Covid levels.

OVERALL IMPACT ON QUALITY OF LIFE

Half of respondents (53%) said their sight loss had a severe or very severe impact on their quality of life (49% in 2022, 53% in 2019).

Chart 03: Quality of life (all respondents)

Right now, what impact does your sight loss condition have on your quality of life overall? Please tick one only.



Those diagnosed more than 20 years ago were more likely to report a severe or very severe impact on their quality of life (60% compared with 40%), as were those registered as severely sight impaired (66%).

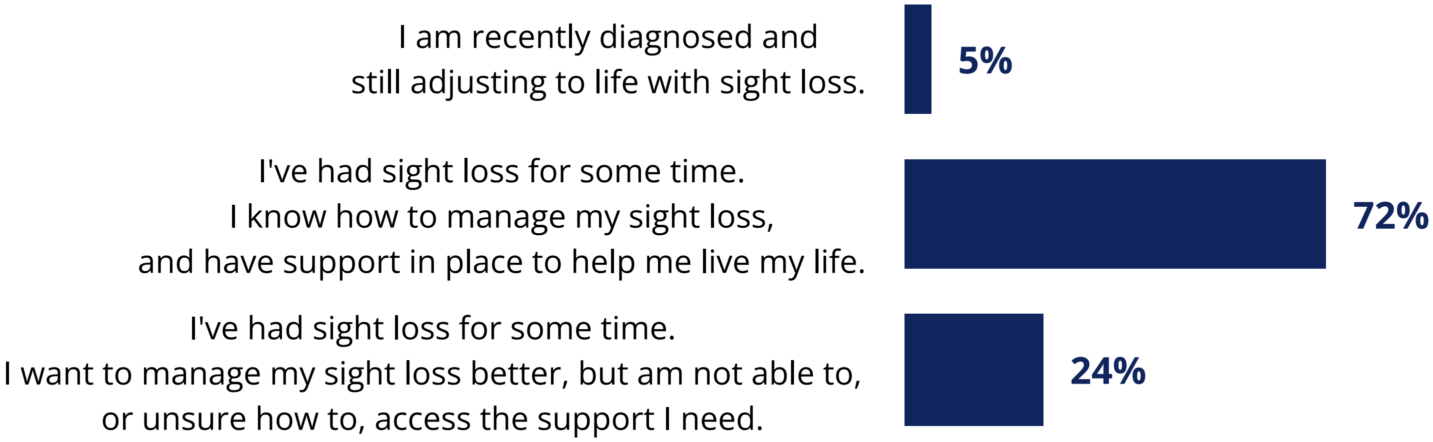
MANAGING THE IMPACT OF SIGHT LOSS

We asked respondents to choose between three statements, reflecting how well they felt they were coping with their sight loss. The results are similar to 2022.

- 5% agreed: 'I am recently diagnosed and still adjusting to life with sight loss.'
- 72% agreed: 'I've had sight loss for some time. I know how to manage my sight loss, and have support in place to help me live my life.'
- 24% agreed: 'I've had sight loss for some time. I want to manage my sight loss better, but am not able to, or unsure how to, access the support I need.'

Chart 04: Coping with sight loss (all respondents)

Which of these statements best describes your current situation? Please select one only.



Three in four (77%) of those diagnosed 20+ years ago said they were managing well, compared with only 60% of those diagnosed more recently.

People who'd had contact with Retina UK were far more likely to say they knew how to manage their sight loss and had support (76% compared with 61% of those not in contact).

Similarly, those with no contact were significantly more likely to say they wanted support but didn't know how to access it (32% compared with 20% who were in contact).

EMOTIONAL AND PSYCHOLOGICAL IMPACTS

We asked people about a range of emotional and psychological impacts resulting from their sight loss. The top five responses were:

Anxiety	77%
Loss of confidence	73%
Stress	62%
Fear	60%
Anger	47%

These are broadly similar to previous surveys, though the proportion of people reporting feelings of anger has slightly increased (47%, from 43% in 2022).

Only 5% said they'd experienced no emotional or psychological impacts.

Those with no contact with Retina UK were far more likely to report 'none of these' impacts. It may mean those with no contact are under-reporting or not acknowledging emotional impact. Or they may experience genuinely fewer impacts and therefore feel less need to reach out.

SPECIFIC QUALITY OF LIFE IMPACTS

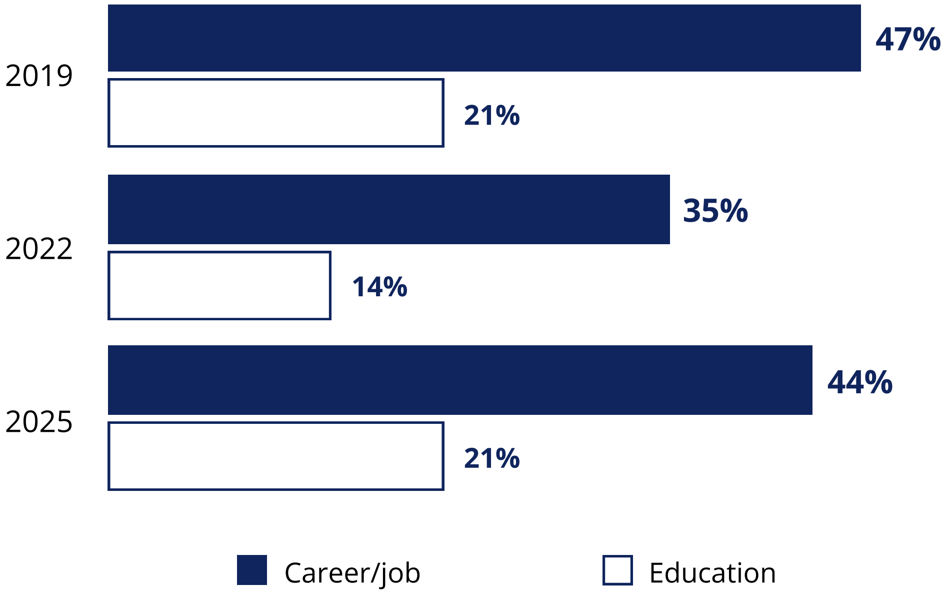
Respondents scored the extent to which their sight loss had affected areas of life, on a scale from ‘not at all’ to ‘extremely’ affected. When ranked by impact, the list is highly similar to previous surveys, with the most affected areas being mobility and getting around, followed by leisure time and hobbies, and social life

	Affected to any degree	Impact is ‘significant’ or ‘extreme’
Mobility and getting around	97%	64%
Leisure time and hobbies	95%	54%
Social life	92%	47%
Career/job	76%	44%
Day-to-day routines	92%	35%
Falls or accidents	89%	28%
Communication	77%	28%
Relationships	71%	23%
Family life	77%	21%
Education	52%	21%

Though the overall percentages of people affected to any degree has not changed, there are differences in the proportion of people for whom the impact is ‘significant’ or ‘extreme’. The areas where this is most marked are education (from 14% in 2022 to 21%), career/job (35% in 2022 to 44%) and relationships (17% in 2022 to 23%).

In 2022, career/job and education impacts were reported as less severe compared with 2019. The 2025 data suggests a negative return to pre-Covid levels of impact.

Chart 05:
Areas ‘significantly’ or ‘extremely’ affected (all respondents)



Those who say they’re not managing their sight loss well overall were more likely to report worse impacts across all areas, compared with those managing well. In particular:

- Family life was more than twice as likely to be significantly or extremely affected (38% compared with 19% of those managing well)
- Education was twice as likely to be affected (34% compared with 17%)
- Relationships were almost twice as likely to be affected (37% compared with 19%)

COMPARISON WITH PREVIOUS SURVEYS

Across the inherited sight loss community, quality of life impacts have changed little over the three surveys. But there are some differences.

Half of respondents (53%) say their sight loss has a severe or very severe impact on their quality of life – slightly higher than in 2022.

There are significantly more people experiencing significant or extreme effects on education, career/job, and relationships. The 2025 data suggests a reversal to pre-Covid levels of impact on education and work.

In 2022, anxiety became the most frequently reported emotional impact, and this has remained the case. The proportion of people reporting feelings of anger has slightly increased.

Services and support

KEY FINDINGS

- Experiences of receiving diagnosis appear to have returned to a positive upward trend, following a dip during the pandemic.
- More people now appear to be signposted to Retina UK, and the proportion offered emotional and psychological support at diagnosis has also increased.
- Just over half of respondents attended an ophthalmology appointment in the past year. One in ten say they don't have an ophthalmologist involved in their care.
- The most useful services for people with sight loss remain: benefits advice; mobility training; access to work schemes; and social services support. There are still unmet needs for support from ECLOs and social services.
- Informal support mostly comes from other national sight loss charities, and informal peer support. Satisfaction with support from Retina UK staff and volunteers has increased significantly since 2019.
- More than one in three respondents (38%) has experienced at least one fall or accident in the past five years that required outside support. The proportion who sought support outside of NHS services has increased since 2022.
- Respondents use a wide range of aids, in particular, in-built accessibility features of smartphones and tablets, and flashlights and illumination devices. Many cite expense as a barrier to accessing aids they'd like, and not knowing how to obtain is also a barrier.

DIAGNOSIS

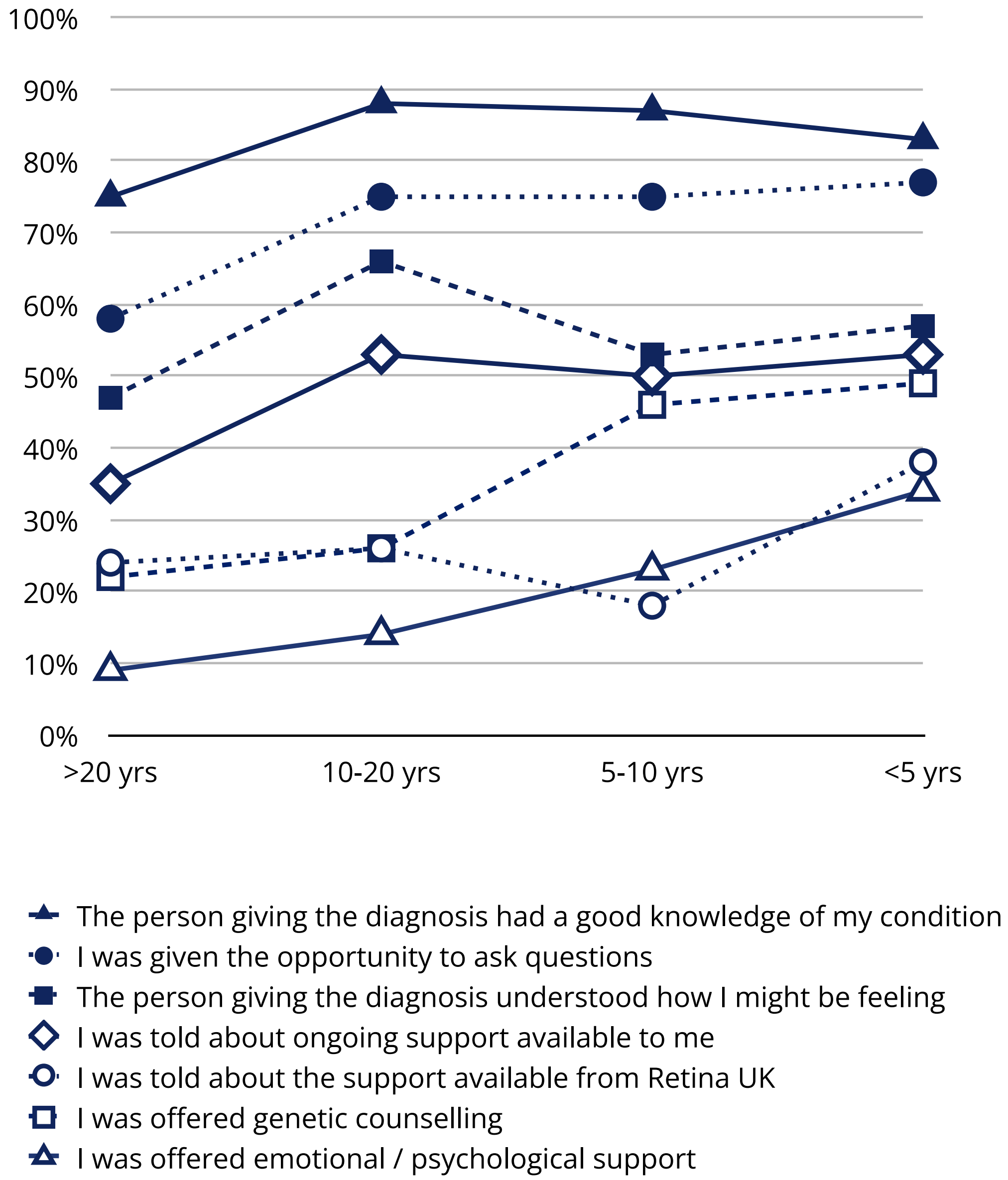
People’s experiences of receiving their diagnosis appear to have improved since a downturn in the pandemic period, resulting in a return to the long-term positive trend we first noticed in 2019.

One area of improvement for those diagnosed in the past five years is that almost four in 10 (38%) were told about the support available from Retina UK, compared with a low of 18% for those diagnosed 5-10 years ago, and an average of 25% for all respondents.

A further positive trend is in the proportion of people being offered emotional or psychological support to adjust to their diagnosis, and there has been an increase in access to genetic counselling.

There continue to be relatively high agreement that the person giving the diagnosis had a good knowledge of the individual’s condition (78%, rising to 83% for those diagnosed in the past five years), and that there was an opportunity to ask questions (62%, rising to 77% for those recently diagnosed).

Chart 06: Experiences of diagnosis (all respondents)



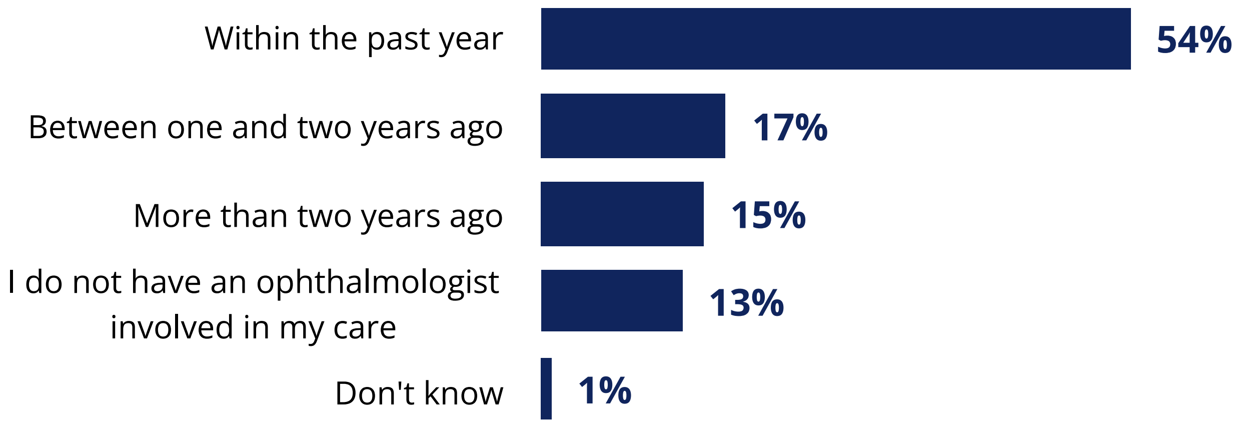
ONGOING SPECIALIST CARE

Just over half of respondents (54%) had attended an appointment with an ophthalmologist (specialist eye doctor) in the past year. A further 17% attended in the past two years.

Those diagnosed within the past 20 years are more likely to have been seen by an ophthalmologist in the past year (66%).

Just over one in 10 (13%) said they do not have an ophthalmologist involved in their care.

Chart 07:
Most recent ophthalmology appointment (all respondents)



SERVICES FOR PEOPLE WITH SIGHT LOSS

We asked respondents about their take-up of services available to people with sight loss, and the extent to which these made a positive difference to their lives. We've ranked these according to the biggest positive difference (totalling 'very' and 'some' positive difference among those who have accessed each service).

		Accessed	Positive difference
1	Advice on claiming benefits	60%	82%
2	Mobility training	57%	81%
3	Access to work scheme	35%	71%
4	Social services support	49%	68%
5	Eye clinic support and signposting (ECLO)	39%	65%
6	Workplace occupational health support	35%	60%
7	Counselling	21%	59%
8	Self-help mental health support (e.g. online)	16%	55%
9 =	Genetic counselling	34%	43%
9 =	Support to change careers	12%	43%
11	Genetic testing	59%	40%

The top three in the list has not changed from the past two surveys, though the 'positive difference' scores for benefits advice and mobility training is slightly lower than in 2022. The proportions who had accessed an access to work scheme or social services support dropped a little, though satisfaction levels remained the same.

Satisfaction with genetic testing had increased in 2022 but this dipped considerably this time, from 65% saying this made a positive difference to only 40%, moving it to the bottom of the list.

We asked about self-help mental health support for the first time. Though only 16% of respondents had accessed this, compared to 21% who had accessed counselling, the positive difference scores were very similar (55% and 59% respectively).

We also asked about barriers that prevented respondents accessing these services. Often, it was because it wasn't a service they needed or wanted. But respondents also told us they were unaware of some services, or that these services were not available to them.

		Accessed	Positive difference	Not aware or not available
1	Advice on claiming benefits	60%	82%	33%
2	Mobility training	57%	81%	34%
3	Access to work scheme	35%	71%	25%
4	Social services support	49%	68%	35%
5	Eye clinic support and signposting (ECLO)	39%	65%	55%
6	Workplace occupational health support	35%	60%	24%
7	Counselling	21%	59%	36%
8	Self-help mental health support (e.g. online)	16%	55%	34%
9 =	Genetic counselling	34%	43%	47%
9 =	Support to change careers	12%	43%	27%
11	Genetic testing	59%	40%	54%

From this we can extract the top five services that respondents haven't accessed – because they didn't know about them, or they were unavailable. This list is the same as in 2022:

1 Eye clinic support and signposting (ECLO)

2 Genetic testing

3 Genetic counselling

4 Counselling

5 Social services support

ECLOs and social services support appear at the top of both lists – they make a positive difference for those who access them, but they are among the hardest services to access.

Analysis of free text responses suggest further barriers:

- Difficulty navigating to support.
- Lack of proactive offers of support.

"I haven't known where to begin to find out how to get help."

"Nothing is ever 'offered' – you have to find out and fight for it."

SUPPORT FROM PEOPLE AND GROUPS

Respondents also accessed charity, community and peer support. We asked which of these sources of support they had accessed, and which made the biggest difference. As before, 'positive difference' is summed from the scores for 'very' plus 'some' positive difference, and excludes those who hadn't accessed this support.

	Accessed	Positive difference
Other national sight loss charities	65%	73%
Informal meetings with others living with sight loss	45%	73%
A local sight loss organisation	54%	71%
Retina UK staff or volunteers	55%	67%
Online sight loss community	39%	55%

As in 2022, highest ratings were given to other national sight loss charities, informal meet-ups and local sight loss organisations. Satisfaction with Retina UK staff and volunteer support has increased slightly, from 63% in 2022 to 67%. This continues the positive trend from 2019, when this figure was 58%.

Respondents' reasons for not accessing these sources of support fell into two categories: they didn't need it, or they couldn't access it.

	I don't need this now	I can't access this
Other national sight loss charities	23%	12%
Informal meetings with others living with sight loss	34%	21%
A local sight loss organisation	29%	17%
Retina UK staff or volunteers	30%	14%
Online sight loss community	36%	25%

Compared with 2022, respondents were less likely to say they needed informal support from others affected (34% compared with 29%). The emphasis on peer support may have faded since the pandemic. There was a small shift in the proportion of respondents unable to access support from other national sight loss charities (12% compared with 7%).

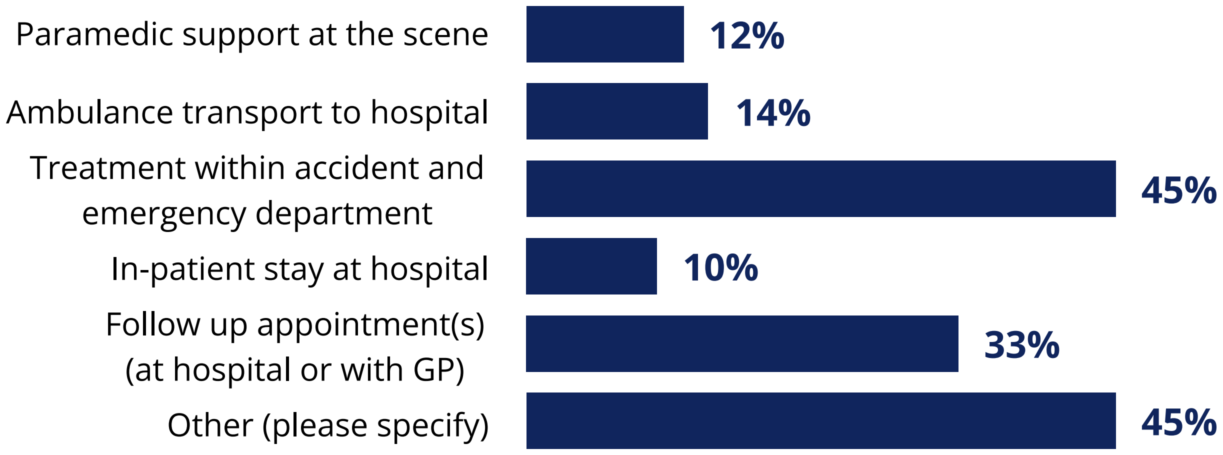
FALLS AND ACCIDENTS

Just over one in three respondents (38%) had experienced a fall or accident related to their sight loss condition in the past five years, that required outside help. This was the same in 2022.

A high proportion (45%) of those ended up being treated in A&E, and one in three (33%) had a follow-up appointment with health services (a slight drop compared with 2022). Around one in 10 cases ended up with paramedic support and/or ambulance transport to hospital (12% and 14% respectively).

The proportion of respondents who sought other forms of help, or managed without, rose from 36% in 2022 to 45% in 2025. Of these, many reported treating themselves for 'minor bumps', getting help from friends or family, or members of the public. Some had sought follow-up support from other kinds of professionals such as opticians and dentists.

Chart 08:
Follow-up care (experienced a fall/accident in the past 5 years)



AIDS, EQUIPMENT AND ASSISTIVE TECHNOLOGIES

Since we first asked about this topic in our 2019 survey, shifting tech and market trends have led to a wider range of assistive technology for people with sight loss. In 2025 we adapted this question to better reflect the current range of aids and equipment.

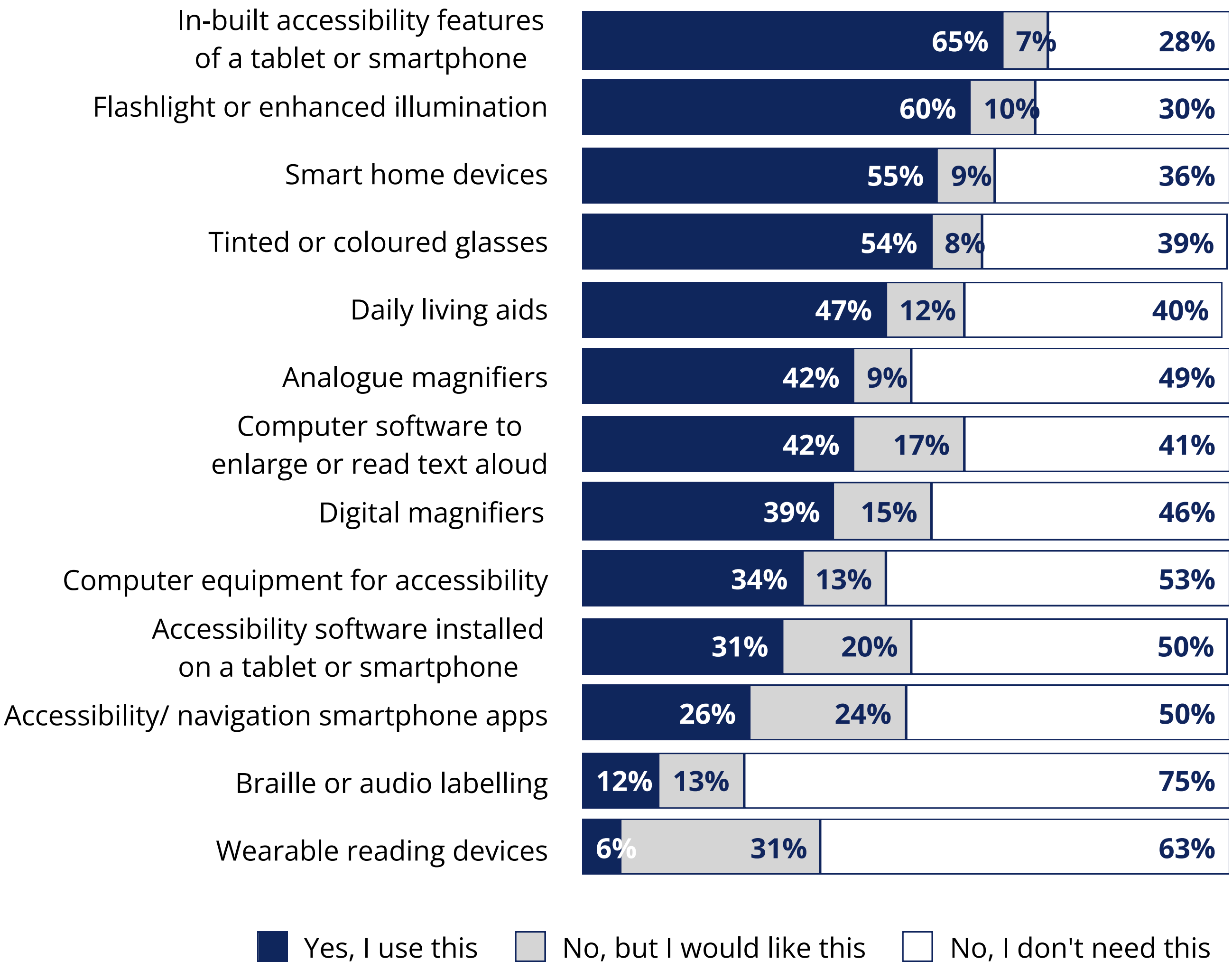
The most widely used on our list were:

	Percentage using
In-built accessibility features of a tablet or smartphone	65%
Flashlight or enhanced illumination	60%
Smart home devices	55%
Tinted or coloured glasses	54%

Though this data isn't directly comparable with previous surveys, it's clear that the proportion of people using smartphone or tablet accessibility features is increasing – around two in three respondents make use of these (65%).

We also asked which equipment or aids respondents would like to use, but don't currently. One in three respondents (31%) would like to access wearable reading glasses (e.g. smart glasses, Orcam). Significant minorities would also be interested in doing more with their smartphones or tablets: one in four (24%) want to try navigation and accessibility apps like Be My Eyes, Seeing AI or Navilens, and one in five (20%) want to try accessibility software such as Synaptic.

Chart 09: Use of aids, assistive technology or communications support (all respondents)



Lack of knowledge on how to obtain items, and cost, were the two main barriers to access. Other barriers included being unaware of the items, and low confidence in use

Don’t know how to obtain	39%
Too expensive	38%
Did not know it existed	27%
Not confident to use	25%
Told it is not suitable or available	5%
Other reason	20%

More respondents cited expense as a barrier compared with 2022 (38% compared with 32%), and lack of awareness is higher (27% compared with 21%). This may be because keeping track of new products, especially tech solutions, is becoming harder.

Analysis of free text responses to ‘other’ indicate further barriers:

- Lack of time to research products
- Aversion to technology

“I don’t do technology very well. Too stressful.”

“Time and support to find, test, experiment and evaluate options.”

COMPARISON WITH PREVIOUS SURVEYS

In 2022, it seemed experiences of diagnosis were getting worse, and we speculated this may be related to the pandemic. Three years on, the picture is more positive. In particular, the proportion of respondents who are now signposted to Retina UK has increased considerably – though it should still be higher.

Satisfaction with genetic testing, which increased in 2022, dipped considerably this time. Satisfaction with ECLO support rose, but there is still a significant unmet need in this area.

Satisfaction with support from Retina UK staff and volunteer support has increased significantly from 2019. But respondents are less likely than in 2022 to feel they need peer support.

The proportion of respondents who sought help outside of NHS services after a fall or accident rose from 36% in 2022 to 45%.

It’s likely more people are using smartphone or tablet accessibility features, compared with previous surveys. Among those who feel they’re missing out, more cited expense as a barrier compared with 2022. Lack of awareness scored higher too, suggesting that keeping track of new products, especially tech solutions, is becoming harder.

Clinical research

KEY FINDINGS

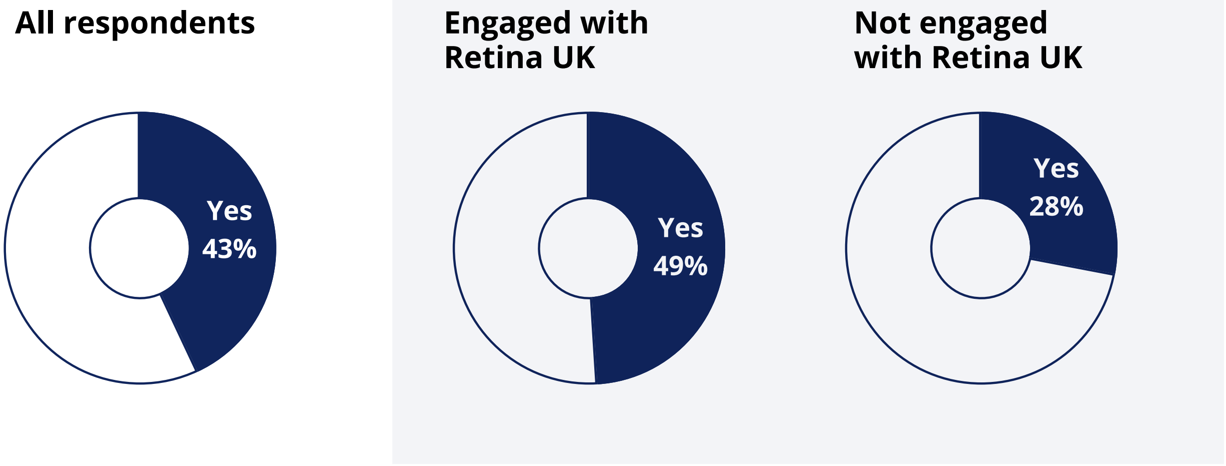
- Just over four in 10 respondents are aware of clinical research into their sight loss, a drop from 2022. But more have participated in research, compared with previous surveys.
- Retina UK remains the top source of research information. As with previous surveys, awareness of research is much higher among those who have engaged with Retina UK compared with those who haven't (49% compared with 28%).

AWARENESS OF CLINICAL RESEARCH

Just over four in 10 respondents (43%) were aware of clinical trials or other ongoing research into their type of sight loss. This is considerably lower than in 2022 (54%) or 2019 (58%).

As with previous surveys, awareness of research was much higher among those who had engaged with Retina UK compared with those who hadn't (49% compared with 28%).

Chart 10: Awareness of clinical trials or other research



SOURCES OF RESEARCH INFORMATION

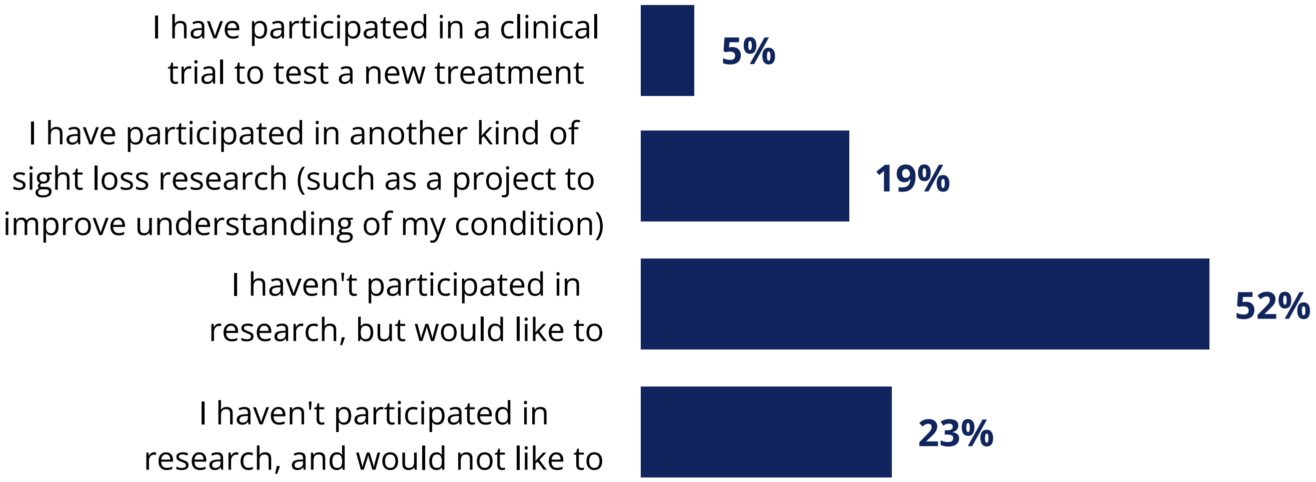
Retina UK remained the top source of research information, with almost two thirds (63%) of those who knew about research citing the charity as the source. Mentions of Retina UK were almost double the next highest source (ophthalmologist).

Retina UK	63%
Opthalmologist	33%
Web search	10%
Charity or patient group (not Retina UK)	9%
Online community	7%
Family member	4%
All other mentions	3% or below

RESEARCH EXPERIENCE AND INTEREST

Although fewer respondents reported knowing about research, there was a small increase in the proportion who said they'd participated in research – 24%, compared with 20% in both 2022 and 2019. A further 52% would like to participate, but haven't yet. And 23% did not want to. These are similar to 2022 and 2019 figures.

Chart 11:
Experience of clinical trials or other research (all respondents)



Mental health

KEY FINDINGS

- One in five respondents (19%) say they have accessed mental health support in relation to their sight loss. Of those who hadn't, 83% said it was because they were not in need of it.
- Of those who had received support, four in five (79%) had accessed talking therapy such as counselling or psychotherapy. Two in five (44%) received prescription medication.
- While half referred themselves for support, the proportion referred by a healthcare professional increased to 40% from 33% in 2022. Respondents reported shorter waiting times, with one in four receiving treatment within two weeks of referral.
- Most benefited to some degree from their mental health support, with a small increase in the minority who said it made managing much easier, from 18% in 2022 to 22%.

MENTAL HEALTH SUPPORT NEEDS

Around one in five respondents (19%) said they had accessed mental health support in relation to their sight loss.

Of those who hadn't, 83% said it was because they were not in need of it. A further 7% said they would like it, but it was not available to them, and 6% said they were unaware of support, or it had never been offered to them.

Among those who said they were not managing well overall, 18% would like mental health support but it was not available to them, and 10% said they were unaware of support, or it had not been offered.

ACCESS TO MENTAL HEALTH SUPPORT

Among those who had accessed mental health support:

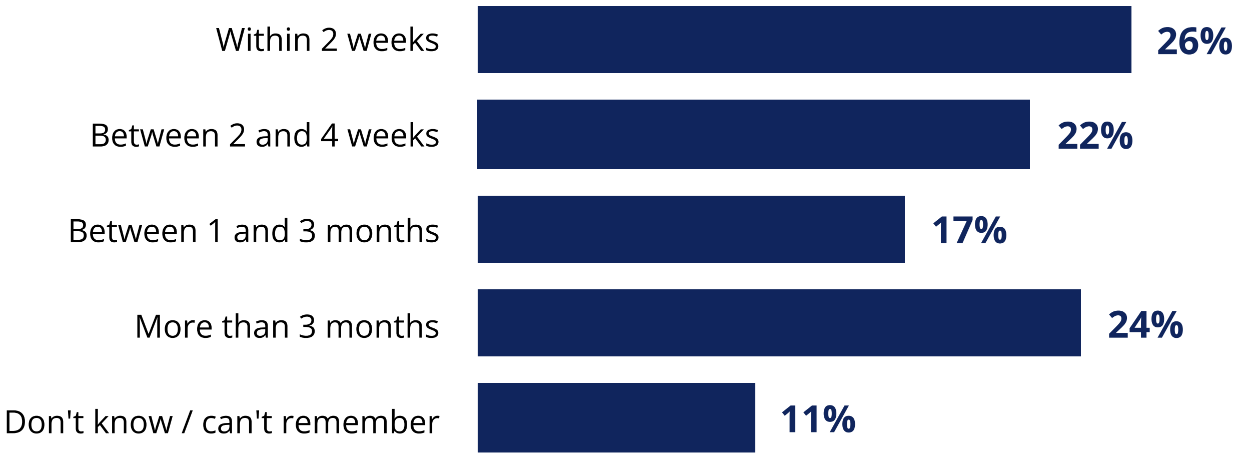
- 79% accessed talking therapies (2022: 80%)
- 44% received prescription medication (2022: 41%)
- 37% used self-help resources, including peer support (2022: 38%)

Half had referred themselves (50%, same as in 2022) and a further four in 10 (40%) had been referred by a health professional, such as GP, compared with 33% in 2022.

Respondents reported shorter wait times for treatment compared with 2022, with a quarter (26%) accessing support within two weeks, compared with only 10% in 2022.

Chart 12: Waiting periods for mental health support

Roughly, how long was the time period from when you first sought mental health support, to when you received this? Select one only.



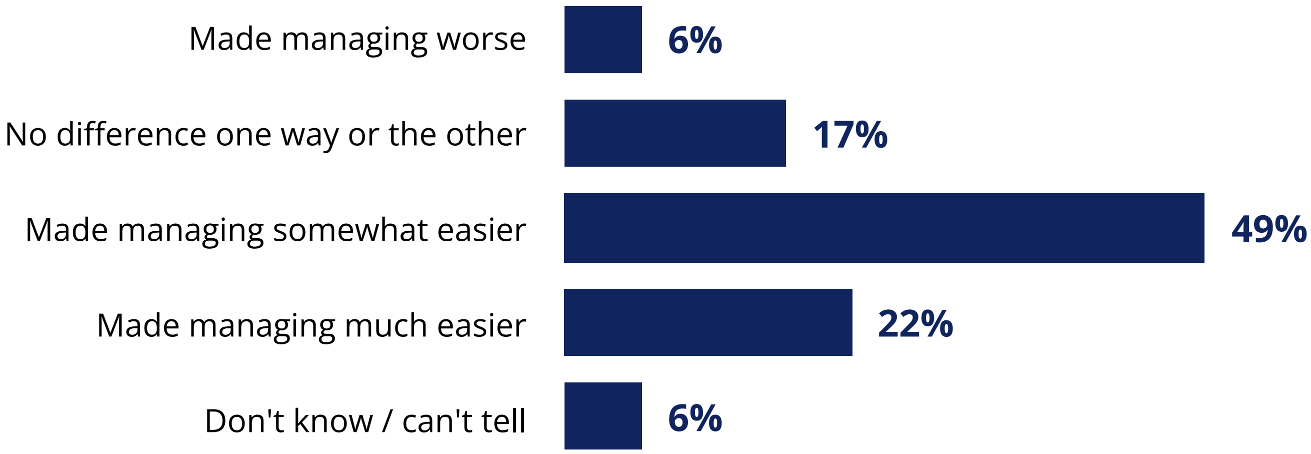
IMPACT OF MENTAL HEALTH SUPPORT

Most respondents had experienced some level of positive benefit from the mental health support they had received: 71% said it had made managing 'much easier' (22%) or 'somewhat easier' (49%). Slightly more respondents said it made managing 'much easier' compared with 2022 (22% compared with 18%).

But for more than one in five (23%) there was either no difference either way (17%) or support had made managing worse (6% – only six respondents). This is similar to 2022.

Chart 13: Impact of mental health support

And how much of a difference has this support made for you? Select one only.



We invited respondents to tell us more about their experiences of mental health and wellbeing support. The themes that came up included:

- On the positive side, the ability to access transformative – even life-saving – support
- Particular praise for charitable or workplace-based access
- Less positively, financial or access barriers, or long waiting times
- Coping without formal support – more common among older respondents

"[I'm] from a generation where we didn't believe in mental health"

"I was worried if I started talking I would completely unravel! I have to hold it together as family do not or are unwilling to acknowledge the difficulties of sight loss."

"[I] stopped thoughts of self-harm."

"It gave me focus and purpose again."

COMPARISON WITH PREVIOUS SURVEYS

The picture is similar to when we first surveyed respondents about mental health support in 2022. There are positive shifts in some responses this time: more respondents say they were referred for mental health support by a healthcare professional, and waiting times to access treatment appear to have improved.

But a quarter of those who don't manage sight loss well still face barriers to accessing support, particularly around lack of availability and lack of awareness of what is on offer.

Attitudes towards Retina UK

KEY FINDINGS

- Online search continues to be the main way newly-diagnosed people find their way to Retina UK, though signposting from health professionals remains a significant referral route.
- Three in four (76%) have engaged with Retina UK in some way – similar to previous surveys.
- Engagement remains highest among those who are: sight loss registered; diagnosed more than 20 years ago; diagnosed with RP; and those who say they're managing their sight loss well.
- Respondents generally agree Retina UK is approachable, trustworthy and ambitious on behalf of people with sight loss. There is broad agreement that the charity listens and responds to people with inherited sight loss.
- One in three rated Retina UK's services and support overall as 'excellent' – higher than in any previous survey.
- Satisfaction was highest with core Retina UK communications: newsletters, website and annual conference.
- More respondents than in 2022 or 2019 agree that, thanks to Retina UK, they have more confidence in managing the challenges of sight loss, and greater awareness of available support.

KNOWING ABOUT RETINA UK

Over a quarter of respondents (28%) heard about Retina UK for the first time from a health professional. This is somewhat skewed by the high proportion of respondents who were diagnosed before, or in the early days of, the internet.

Those diagnosed more recently (within the past 20 years) are most likely to have found Retina UK through an online search. This continues the shift noted in 2019 and 2022, from people relying on word of mouth to finding the charity through the internet.

The top ways people hear about us:

	All	Diagnosed up to 20 years ago	Diagnosed more than 20 years ago
From a healthcare professional	28%	24%	30%
Word of mouth	16%	11%	18%
Internet search	15%	27%	10%
Another charity or support group	14%	16%	13%
In the media	9%	9%	9%
Social media	5%	6%	5%
Via a family member	4%	5%	4%
Not before this survey	1%	1%	1%

ENGAGING WITH RETINA UK

Three in four respondents (76%) said they had engaged with Retina UK in some way. This is slightly lower than in 2022 (80%), and may be related to how the survey was distributed among the wider inherited sight loss community.

Respondents had engaged through one or more of the following routes:

Member	47%
Access info and/or support	44%
Donate or raise funds	40%
Belong to Peer Support Group	11%
Volunteer	5%
Paid staff member	1%
None of these	24%

Compared with 2022, there was a lower representation of Members (47% compared with 54%), though most other roles scored similarly.

As with previous surveys, engagement with Retina UK was higher among:

- Those who said they were currently managing their sight loss well, compared with those who said they were not managing well (79% compared with 67%).
- Those diagnosed with RP (retinitis pigmentosa) compared with those with other diagnoses (80% compared with 69%).
- Those diagnosed more than 20 years ago, compared with those diagnosed since then (78% compared with 70%).
- Those who were sight loss registered, compared with those not registered (77% compared with 69%).

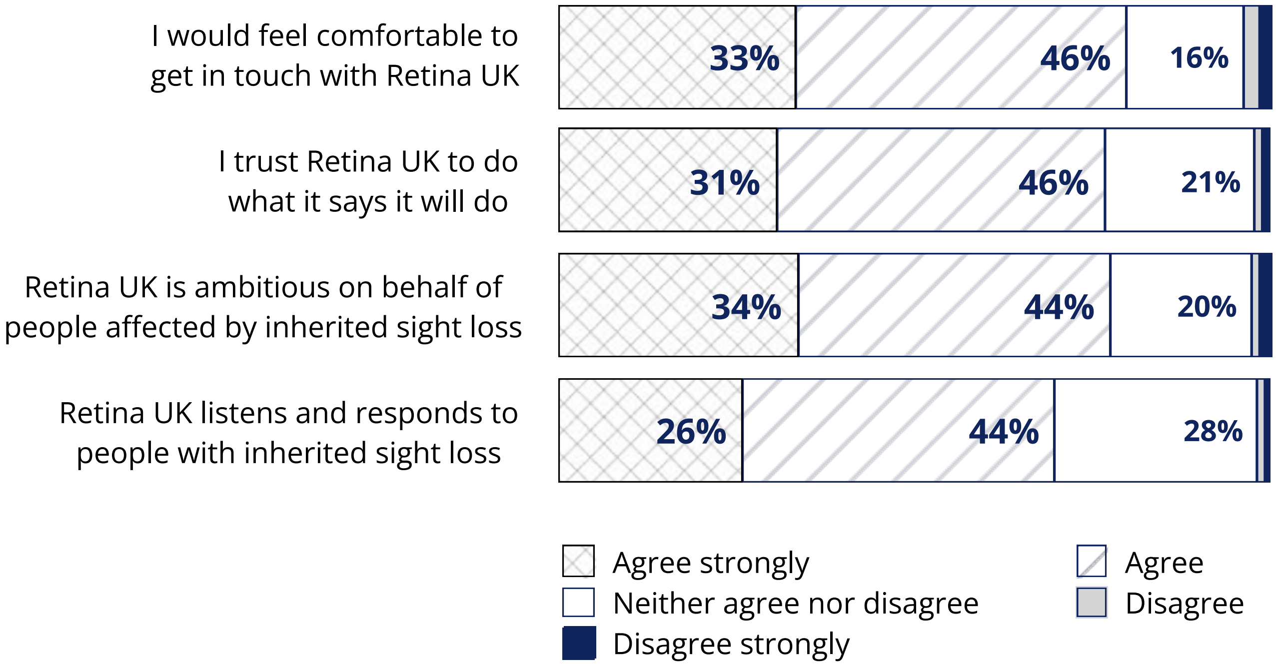
PERCEPTIONS OF RETINA UK

Respondents were generally happy to agree that Retina UK behaves in line with its values: by being approachable, ambitious and trustworthy.

There were significant minorities unsure one way or the other, but very little active disagreement. This is similar to previous surveys.

Agreement was a little lower – though still high – on a new statement we tested: that Retina UK 'listens and responds to people with sight loss'. Over one in four respondents were 'neutral' on this – the highest proportion of 'unsure' respondents – but almost no one disagreed.

Chart 14: Beliefs about Retina UK (all respondents)

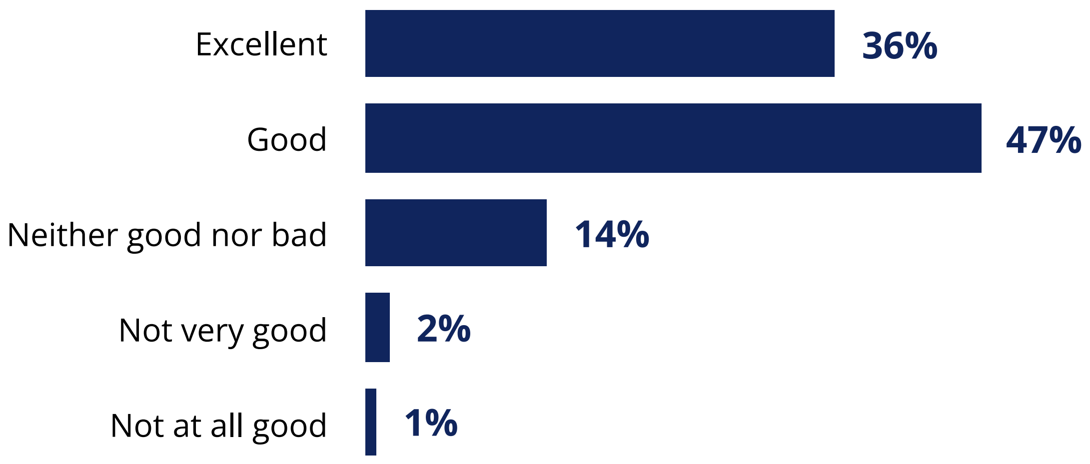


RETINA UK INFORMATION, SUPPORT AND SERVICES

Overall satisfaction with Retina UK's information, support and services is significantly higher in 2025 than in the previous two survey periods. The proportion of respondents who rate Retina UK's services overall as 'excellent' has increased: from 27% in 2019, and 29% in 2022, to 36% in 2025.

As with previous surveys, the proportion who say services are 'not very' or 'not at all' good remains at just 3%.

Chart 15: Rating information, support and services from Retina UK (users of services only)



Satisfaction was highest with core Retina UK communications: newsletters, website and annual conference. Adoption of webinars has increased since 2022 (from 12% to 19%), though it appears there is an opportunity to broaden access further, given their popularity. It's a similar picture with the website (only 51% of service users engage this way) and the annual conference.

No service scored below 80% for net satisfaction (calculated by totalling 'very' and 'quite' satisfied).

	Accessed	Satisfied
Regular newsletters	80%	97%
Website	51%	94%
Annual conference	24%	93%
Webinars	19%	91%
Support with fundraising	19%	88%
Helpline	26%	88%
Facebook support groups	17%	87%
Peer Support Groups (online or face to face)	26%	86%
Podcasts	10%	84%
Discover Wellbeing online service	8%	83%
Talk and support (telephone befriending service)	9%	80%

Changes to uptake and satisfaction compared with 2022:

- As mentioned, uptake of webinars increased from 12% in 2022 to 19% in 2025.
- Participation in the annual conference (online or in person) is now at 24%, a little higher than in 2022 (21%) and significantly higher than in 2019 (16%).
- Satisfaction with helpline, support with fundraising, and Facebook support, are all lower than in 2022 – though all still score highly.
- Telephone befriending has maintained 2022 satisfaction levels, after only scoring 73% in 2019. Though still not widely used, it's become more popular – now being accessed by 9% of service users (5% in 2022).

SUPPORTING RETINA UK

Two in three respondents (66%) have supported Retina UK through donations or fundraising. This is lower than in 2022 (72%).

Propensity to support Retina UK is higher among:

- Those diagnosed more than 20 years ago, compared with those diagnosed since then (74% compared with 49%).
- Those who say they're managing well, compared with those who say they're not (70% compared with 58%).

Respondents were invited to say more about why they do or don't support Retina UK.

SUPPORTING RETINA UK: KEY THEMES

- Personal connection to inherited sight loss / retinitis pigmentosa
  "Because it is important to my family, especially my mum who has RP."
- Belief in Retina UK's mission and impact
  "I feel that Retina UK are supporting community and research."
- Giving back and showing gratitude
  "I'm very grateful for the support I've had."
- Legacy and long-term hope
  "To help ensure future generations don't have to live with RP."

NOT SUPPORTING RETINA UK: KEY THEMES

- Financial or time constraints
  "No spare time or money – sorry."
- Lack of awareness
  "Sorry, we don't know much about your charity."
- Past involvement but no longer active
  "I was part of the Retina UK Lottery, but had to stop."

THE DIFFERENCE RETINA UK MAKES

Eight in 10 respondents (81%) agreed that, thanks to Retina UK, they were better informed about ongoing research. This is significantly higher among those diagnosed more than 20 years ago, and lower for those diagnosed since then (87% compared with 68%).

More than half (57%) said Retina UK helped them have greater awareness of available support. This is a significant increase on previous surveys (50% in 2022, 45% in 2019) and suggests a positive upwards trend. Agreement was higher among those sight loss registered, compared with those not registered (58% compared with 48%).

There was also an increase in the proportion of respondents who said that thanks to Retina UK, they felt more confident to manage the challenges of their sight loss – from one in five in 2022 (20%), to one in three (32%) in 2025.

Some of this increase may be explained by a change in question design, to reduce the number of choice options. However, it was always possible to select all statements that applied, making it unlikely the redesign alone accounts for such positive shifts.

Chart 16: What difference does Retina UK make to you? (all respondents)

RETINA UK'S FUTURE DIRECTION

We asked respondents which of the charity's three areas of work they would like to see greatest focus on in the next three years.

Just over half (54%) said the focus should be on 'funding and promoting research for causes and treatments for inherited sight loss' – the same as in 2022.

The remainder were evenly split between 'providing information and support to help people manage their inherited sight loss' (24%) and 'increasing society's understanding of the needs of people with inherited sight loss (22%). Again, these are similar to the 2022 results.

Chart 17: What should Retina UK concentrate our efforts on most over the next three years?

COMPARISON WITH PREVIOUS SURVEYS

Overall satisfaction with Retina UK's information, support and services is significantly higher in 2025 compared with the previous two survey periods, as measured by the proportion of respondents who score these as 'excellent'.

As ever, satisfaction levels vary between products and services, highlighting areas where take-up can be broadened or improvements made.

There is higher agreement with two key measures of impact: that Retina UK provides greater awareness of available support, and that the charity helps people feel more confident in managing the challenges of their sight loss.

RETINA UK

WORKING FOR PEOPLE WITH INHERITED SIGHT LOSS

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