

# RETINA UK SIGHT LOSS SURVEY 2022

Findings from our survey  
of almost 700 people living  
with inherited sight loss.

July 2022

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# WELCOME FROM OUR CHIEF EXECUTIVE

Retina UK is the only UK charity dedicated solely to working for people affected by inherited sight loss. We support people affected by inherited sight loss lead better lives today, and fund medical research to accelerate the search for treatments for the future.

A huge thank you to everyone who took the time to complete the survey in 2022, this feedback is essential to Retina UK reflecting the inherited sight loss community and your wishes. Your valuable input allows us to measure what impact our work has had over the past three years and tells us where we should focus efforts over the next three years.

The Covid-19 pandemic and associated lockdowns have had a significant impact on the entire world, including people living with sight loss. The responses in 2022 will naturally reflect those experiences and, importantly, how we can support you, and the cause, in the best way.

Your feedback in 2019 informed our work over the past three years and the results of our 2022 survey will dictate the future of Retina UK's work.

Thank you again.

**Tina Garvey**  
Chief Executive  
Retina UK

## 01 INTRODUCTION

Retina UK first undertook a comprehensive survey of the experiences of people with inherited sight loss in 2019. The aim then was to better understand people's views and experiences, and we used what we learned to improve our support.

In 2022, we repeated the survey, to understand what has changed since 2019, and incorporate findings into our future plans. We took the opportunity to ask about areas we didn't cover the first time: about the quality and accessibility of mental health support available to people with inherited sight loss, and experiences of falls and accidents.

As in 2019, our questionnaire was designed to be completed by anyone living with inherited sight loss (or by their parent or guardian if they were under 18). We tested the draft questionnaire with people with sight loss, to check that the questions and response options were appropriate, and made changes to new questions based on their feedback. The questionnaire covered:

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

The questionnaire was made available for online completion and as a printed booklet. It was distributed by post with copies of our magazine Look Forward, and 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 673 responses.

## 02 SUMMARY OF KEY FINDINGS

### TYPES OF SIGHT LOSS

- Most respondents are sight loss registered (87%, compared with 84% in 2019).
- Two thirds (67%) have been diagnosed with RP (retinitis pigmentosa).
- Two thirds (68%) were diagnosed over 20 years ago – similar to 2019 levels (61%).
- Almost a third (31%) can name the gene or genetic disease type causing their sight loss – this is twice the percentage in 2019, and suggests a positive increase in the number of people who are given a genetic diagnosis.
- 5% have no vision at all, and 4% have good overall vision.

### QUALITY OF LIFE

- Half of respondents (49%) say their sight loss has a severe or very severe impact on their quality of life.
- Three quarters (74%) say they're managing their sight loss well, compared with 22% who say they want to be able to manage it better.
- Anxiety, loss of confidence and stress are the biggest emotional or psychological impacts of sight loss. Only 7% say they've experienced no impacts like these.
- Those who have engaged with Retina UK are less likely to say they've experienced loneliness, isolation and depression, compared with those who have not engaged.
- Sight loss particularly impacts on mobility and getting around; leisure time and hobbies; and social life.

## SERVICES AND SUPPORT

- The previous 20-year positive trend in people's experiences of receiving their diagnosis has not continued, and may in fact have reversed. This may be related to changes in the way the diagnosis was made and communicated during the pandemic.
- In particular, people diagnosed more recently were less likely to believe the person giving the diagnosis understood how they felt, or to be told about ongoing support available to them (but note that respondent numbers are small).
- The most useful services for people with sight loss are: benefits advice; mobility training; access to work schemes; and social services support. Despite improvements, there is still unmet demand for genetic testing and social services support, and also for counselling.
- Compared with 2019, there appears to be a larger role for community-based support – whether through local organisations, or informal meetings with others affected by sight loss.
- More than one in three respondents (39%) has experienced at least one fall or accident in the past five years related to their sight loss, with half of those (49%) receiving treatment in A&E as a result.
- Respondents access a wide range of aids, with half now using Alexa-style smart home devices and smartphones with accessibility features. The two main barriers to accessing aids are not knowing how to obtain these, and cost.

## CLINICAL RESEARCH

- More than half (54%) are aware of clinical research into their type of sight loss, and 20% have participated in research.
- Retina UK is the top source of research information. As in 2019, awareness of research is much higher among those who have engaged with Retina UK compared with those who haven't (59% compared with 38%).

## MENTAL HEALTH

- A relatively small percentage of respondents (16%) have accessed mental health support in relation to their sight loss. Rates are *slightly lower* among those diagnosed more than 20 years ago, and those aged over 55.
- Of those who haven't, 80% said it was because they were not in need of it. This is despite 93% saying they experienced negative emotional or psychological impacts related to their sight loss.
- Of those who have received support, four in five have accessed a talking therapy such as counselling or psychotherapy. Two in five (41%) received prescription medication.
- Half had referred themselves, and a further third were referred by a health professional.
- Most benefited to some degree from their mental health support, though respondents were more likely to say it made managing 'somewhat' easier (56%), rather than 'much' easier (18%).

## ATTITUDES TO RETINA UK

- Those diagnosed more recently are most likely to have found about Retina UK from an internet search, while those diagnosed longer ago were signposted by a healthcare professional.
- Eight in 10 (80%) have engaged with Retina UK in some way – a higher percentage than in 2019.
- Engagement is higher among those: sight loss registered; diagnosed more than 20 years ago; diagnosed with RP; and who say they're managing their sight loss well.
- Respondents mostly agree Retina UK is approachable, trustworthy and ambitious on behalf of people with sight loss. Compared with 2019, more agree people with sight loss have a big say in what the charity does.
- Almost nine in 10 (88%) agree that, thanks to Retina UK, they are better informed about ongoing research.



- 83% rate Retina UK's services as 'excellent' or 'good'.
- Newsletters achieve highest satisfaction and usage levels, followed by the website. There have been increases in satisfaction and take-up among many aspects of Retina's services, compared with 2019.
- More than half of respondents have donated or fundraised for Retina UK, with support levels higher among those diagnosed more than 20 years ago, and among those managing their sight loss well.
- Most people would like to see Retina UK focus mostly on research over the next three years, with the remainder equally split between wanting to see a focus on support provision and wanting to see a focus on improving societal understanding.

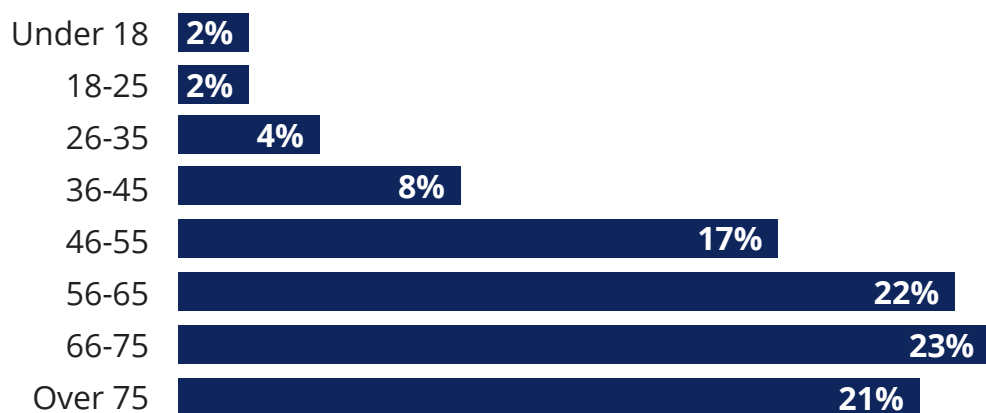
## 03 ABOUT THE RESPONDENTS

### KEY FINDINGS

Of the 673 individuals who responded:

- 96% completed the survey on their own behalf (92% in 2019), and 4% were the parent/guardian responding on behalf of a child aged under 18 (8% in 2019).
- Just over half identified as female (57%) and just under half as male (43%).
- 94% 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:

### RESPONDENT AGES (ALL RESPONDENTS)



Retired	55%
Employed full time	16%
Not in paid work	13%
Employed part time (working 30 hours or less)	8%
Doing voluntary work	7%
In full or part-time education or training	4%
Self-employed part time	3%
Self-employed full time	1%
Other	6%

## GROUPING RESPONDENTS FOR ANALYSIS

We allocated respondents into pairs of groups, based on their responses to four particular questions. We then used these groups to look for correlations between these questions and responses to other parts of the survey.

### Sight loss registered (87%)

**Q: Are you registered as severely sight impaired or sight impaired?**

Responded:

- Yes, I am registered as severely sight impaired *or*
- Yes, I am registered as sight impaired

### Not registered (13%)

**Q: Are you registered as severely sight impaired or sight impaired?**

Responded:

- No, my degree of sight loss does not meet the criteria *or*
- No, I have chosen not to be registered

### Diagnosed less than 20 years ago (32%)

**Q: How long ago were you diagnosed with your sight condition?**

Responded with one of:

- Within the past 12 months
- Between 1 and 5 years ago
- Between 5 and 10 years ago
- Between 10 and 20 years ago

### Diagnosed more than 20 years ago (68%)

**Q: How long ago were you diagnosed with your sight condition?**

Responded:

- More than 20 years ago

### Currently managing well (74%)\*

**Q: Which of these statements best describes your current situation?**

Responded:

- 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.

### Not currently managing well (22%)\*

**Q: Which of these statements best describes your current situation?**

Responded:

- 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.

## Have engaged with Retina UK (80%)

Q: Here are some ways people get involved with Retina UK. Which of them apply to you?

Responded with one or more of:

- I access information and/or support
- I am a member
- I belong to a Local Group
- I donate or raise funds
- I am a volunteer
- I am a paid member of staff

## Have not engaged with Retina UK (20%)

Q: Here are some ways people get involved with Retina UK. Which of them apply to you?

Responded with:

- None of these

\*These two percentages do not add up to 100%, as we've omitted the 4% of respondents who selected a third option to this question: 'I'm recently diagnosed, and still adjusting to life with sight loss.'

## COMPARISON WITH 2019

The demographic profile of respondents was broadly similar in 2019. There were 673 respondents, compared to 924 in 2019. The primary form of distribution of the paper version survey this time was a joint mailing with Retina UK’s magazine *Look Forward*, instead of a standalone mailing. A link was also emailed to more individuals on Retina UK’s database.

	2019	2022
<b>Direct postal mailing to individual records</b>	2,600	
<b>Postal mailing sent with <i>Look Forward</i></b>		3,700
<b>Email mailing with link</b>	2,000	3,336
<b>General promotion</b>	Staff, trustees, volunteers, professionals, sector partners, RNIB radio, research community, social media channels, Look Forward article, e-newsletter	

It is unclear why this survey received a lower response rate compared with 2019. It may be that:

- Packaging the paper version of the survey with another product resulted in people not noticing it so readily
- Emailing a larger proportion of Retina UK’s ‘base’ led to surveys reaching more people with only a distant relationship to the charity, where motivation to complete may be lower

## 04 TYPES OF SIGHT LOSS

### KEY FINDINGS

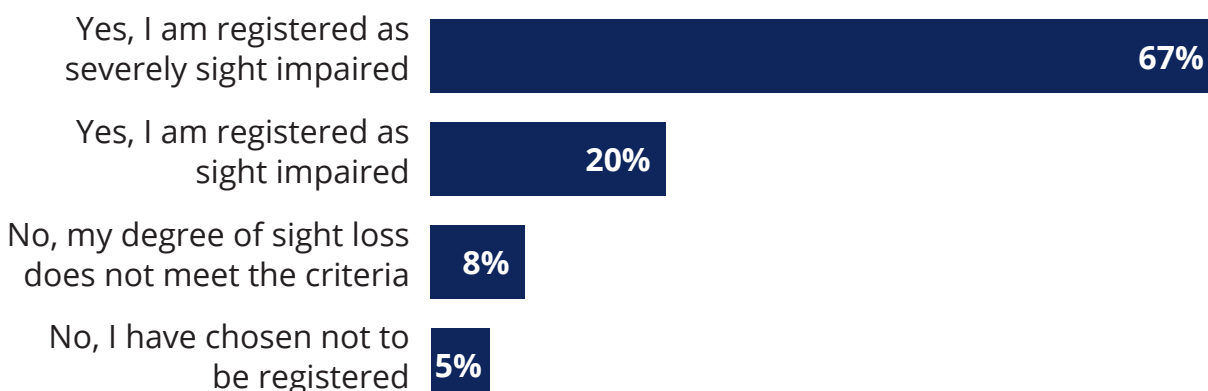
- Most respondents are sight loss registered (87%, compared with 84% in 2019).
- Two thirds (67%) have been diagnosed with RP (retinitis pigmentosa).
- Two thirds (68%) were diagnosed over 20 years ago – similar to 2019 (61%).
- Almost a third (31%) could name the gene or genetic disease type causing their sight loss – this is twice the percentage in 2019, and suggests a positive increase in the number of people who are given a genetic diagnosis.
- 5% have no vision at all, and 4% have good overall vision.

### SIGHT LOSS REGISTRATION

Most respondents (87%) were either registered as sight impaired (20%) or severely sight impaired (67%). Those not registered comprised 8% who said their degree of sight loss did not meet the criteria for registration, and 5% who said they had chosen to not be registered.

#### SIGHT LOSS REGISTRATION (ALL RESPONDENTS)

**Are you registered as severely sight impaired or sight impaired?  
Please tick one only.**



## DIAGNOSED CONDITION

Two thirds of respondents (67%) had been diagnosed with RP (retinitis pigmentosa). The remaining 33% had a range of other conditions. The most frequently mentioned were Usher syndrome (12%) and Stargardt disease (2%).

Classic retinitis pigmentosa (RP)	67%
Usher syndrome	12%
Stargardt disease	2%
Bardet-Biedl syndrome	2%
Cone-rod dystrophy	1%
Choroideremia	1%
Rod-cone dystrophy	1%
Leber congenital amaurosis	1%
Other	12%

## GENETIC DIAGNOSIS

Almost four in 10 (39%) of respondents said they had received a genetic diagnosis for their sight condition.

Analysis of free text responses shows 31% of all respondents were able to provide the name of a gene or specific type of RP (which correlates to a specific gene).

This is almost twice as many (as a percentage) as in 2019, when only 15% of all respondents could provide a recognisable gene / genetic disease type. This suggests a considerable increase in the proportion of people with inherited sight loss who are able to find out their specific genetic diagnosis.

## TIME SINCE DIAGNOSIS

Two thirds of respondents (68%) were diagnosed over 20 years ago:

Past 12 months	1%
1 – 5 years ago	6%
5 – 10 years ago	7%
10 – 20 years ago	18%
Over 20 years ago	68%

Those diagnosed more than 20 years ago were more likely to be sight loss registered compared with those diagnosed less than years ago (93% compared with 73%). This is similar to 2019.

## REMAINING VISION

As in 2019, respondents reported different degrees and types of remaining vision. Almost one in 20 (5%) had no vision at all, while 4% still had good overall vision. Many of those who answered ‘other’ said they experienced ‘night blindness’ or had lost vision in one eye only.

No vision	5%
Light perception only (or shadows only)	15%
Some useful central vision	46%
Good central vision	28%
Some useful peripheral vision	17%
Good peripheral vision	4%
Good overall vision	4%
Other	7%

## COMPARISON WITH 2019

The big change here is in the proportion of people who can name the gene causing their sight loss, or genetic disease type. This percentage has doubled since 2019, suggesting an improvement in genetic diagnosis and information sharing with patients.



## 05 QUALITY OF LIFE

### KEY FINDINGS

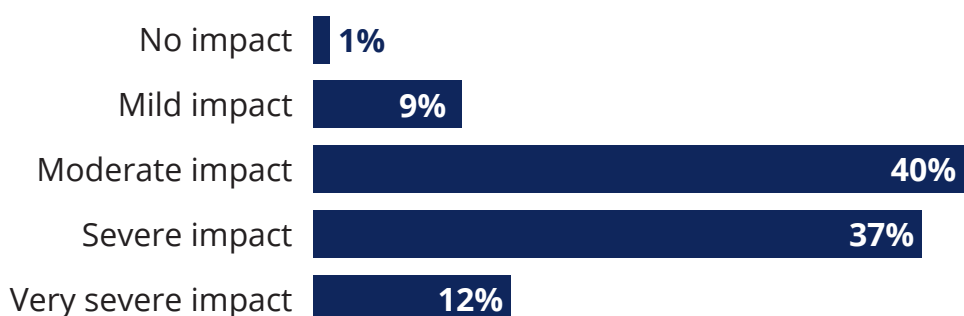
- Half of respondents (49%) say their sight loss has a severe or very severe impact on their quality of life.
- Three quarters (74%) say they're managing their sight loss well, compared with 22% who say they want to be able to manage it better. Those managing well include higher proportions of people diagnosed more than 20 years ago, and people who engage with Retina UK, compared with those not managing well.
- Anxiety, loss of confidence and stress are the biggest emotional or psychological impacts of sight loss. Only 7% say they've experienced no impacts like these.
- Those who have engaged with Retina UK are less likely to say they've experienced loneliness, isolation and depression, compared with those who have not engaged.
- Sight loss particularly impacts on mobility and getting around; leisure time and hobbies; and social life.

### OVERALL IMPACT ON QUALITY OF LIFE

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

### 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 over 20 years ago were considerably more likely to say the impact on their quality of life was severe or very severe, compared with those diagnosed since (57% compared with 33%).

Those who are sight loss registered were much more likely to say their sight loss had a severe or very severe impact on their quality of life – 53% said this, compared with only 8% of those not registered. However, this is a considerable improvement compared with 2019, when 85% of those who are sight loss registered said their condition had a severe or very severe impact on their quality of life.

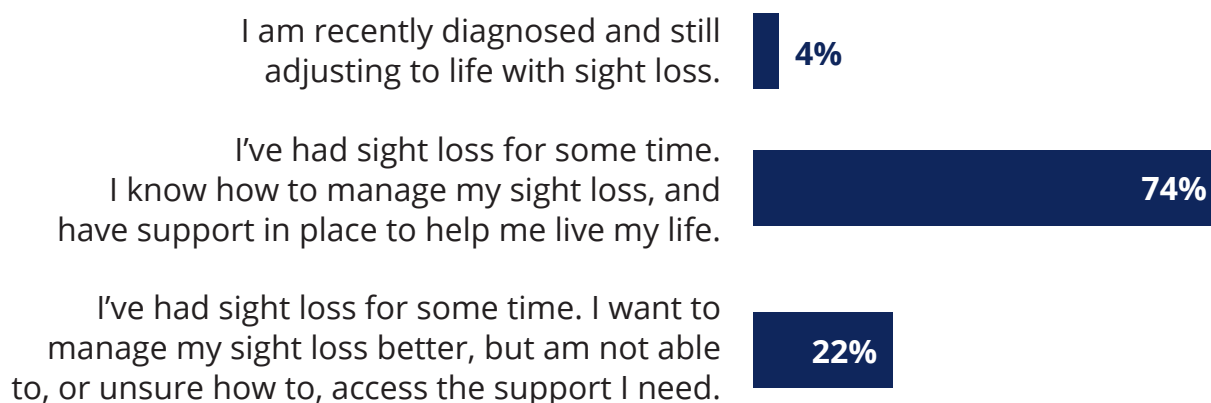
### MANAGING THE IMPACT OF SIGHT LOSS

We asked respondents to choose between three statements, reflecting how well they feel they are coping with their sight loss right now.

- 4% agreed: 'I am recently diagnosed, and still adjusting to life with sight loss.'
- 74% 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.'
- 22% 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.'

### COPING WITH SIGHT LOSS (ALL RESPONDENTS)

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



Almost three quarters (73%) of those who said they are managing well were diagnosed with sight loss more than 20 years ago, compared with 65% of those who say they're not managing well.

Those who say they are currently managing their sight loss well are more likely to have engaged with Retina UK, compared with those who say they are not managing well (83% compared with 75%).

## 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	78%
Loss of confidence	74%
Stress	63%
Fear	58%
Anger	43%

While this is broadly similar to 2019, the increase in people experiencing anxiety (78% compared with 71% in 2019) is noteworthy. This has moved from second to first in the ranking list.

Only 7% said they'd experienced no emotional or psychological impacts.

People who have engaged with Retina UK were less likely to report loneliness, isolation and depression compared with those who have not engaged:

- 31% of those who have engaged with Retina UK said they experienced loneliness, compared with 52% of those who have not engaged.
- 36% said they experienced isolation, compared with 49% of those who have not engaged.
- 37% said they experienced depression, compared with 47% who have not engaged.

## SPECIFIC QUALITY OF LIFE IMPACTS

Respondents scored the extent to which their sight loss had affected particular areas of their lives, on a scale from 'not at all' to 'extremely'. As in 2019, ranking by impact shows the most affected areas are 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	98%	63%
Leisure time and hobbies	96%	52%
Social life	91%	43%
Career / job	77%	35%
Day-to-day routines	93%	31%
Falls or accidents	90%	29%
Communication	79%	24%
Family life	74%	18%
Relationships	71%	17%
Education	57%	14%

While this table looks very similar to 2019, there are small but interesting reductions in the proportion of people experiencing significant or extreme impacts on 'career / job' (35% vs 47% in 2019) and 'education' (14% vs 21% in 2019). It's not clear why this is the case, but it could be a pandemic impact – with employers and schools finding alternative ways to ensure access.

Those who said they are not currently managing their sight loss well were more likely to score all of these impacts as high, when compared with those who say they are managing well.

The differences between these two groups are particularly marked when it comes to:

- Social life (69% of those not managing well say this is 'significantly' or 'extremely' affected, compared with 38% of those managing well)
- Day-to-day routines (51% compared with 28%)
- Leisure time and hobbies (70% compared with 20%)
- Falls or accidents (46% compared with 26%)

### COMPARISON WITH 2019

People who are sight loss registered are much less likely to say their sight loss has a severe or extremely severe impact on their quality of life (53% in 2022 compared with 85% in 2019).

Anxiety is a slightly bigger issue than in 2019, and now tops the list of negative emotional impacts.

The impact of sight loss on career / job and education is less severe overall compared with 2019.

## 06 SERVICES AND SUPPORT

### KEY FINDINGS

- The previous 20-year positive trend in people's experiences of receiving their diagnosis has not continued, and may in fact have reversed.
- In particular, people diagnosed more recently were less likely to believe the person giving the diagnosis understood how they felt, or to be told about ongoing support available (but note that respondent numbers are small).
- The most useful services for people with sight loss are: benefits advice; mobility training; access to work schemes; and social services support. Despite improvements, there are still unmet needs on genetic testing and social services support, and also for counselling.
- Compared with 2019, there appears to be a larger role for community-based support – whether through local organisations, or informal meetings with others affected by sight loss.
- More than one in three respondents (39%) has experienced at least one fall or accident in the past five years related to their sight loss, with half of those (49%) receiving treatment in A&E as a result.
- Respondents access a wide range of aids, with half now using Alexa-style smart home devices and smartphones with accessibility features. The two main barriers to accessing aids are not knowing how to obtain these, and cost.

## DIAGNOSIS

In 2019, we found that people's experience of receiving their diagnosis appeared to have improved over the past 20 years, and to be on an upward trajectory. Three years on, and that is no longer the case.

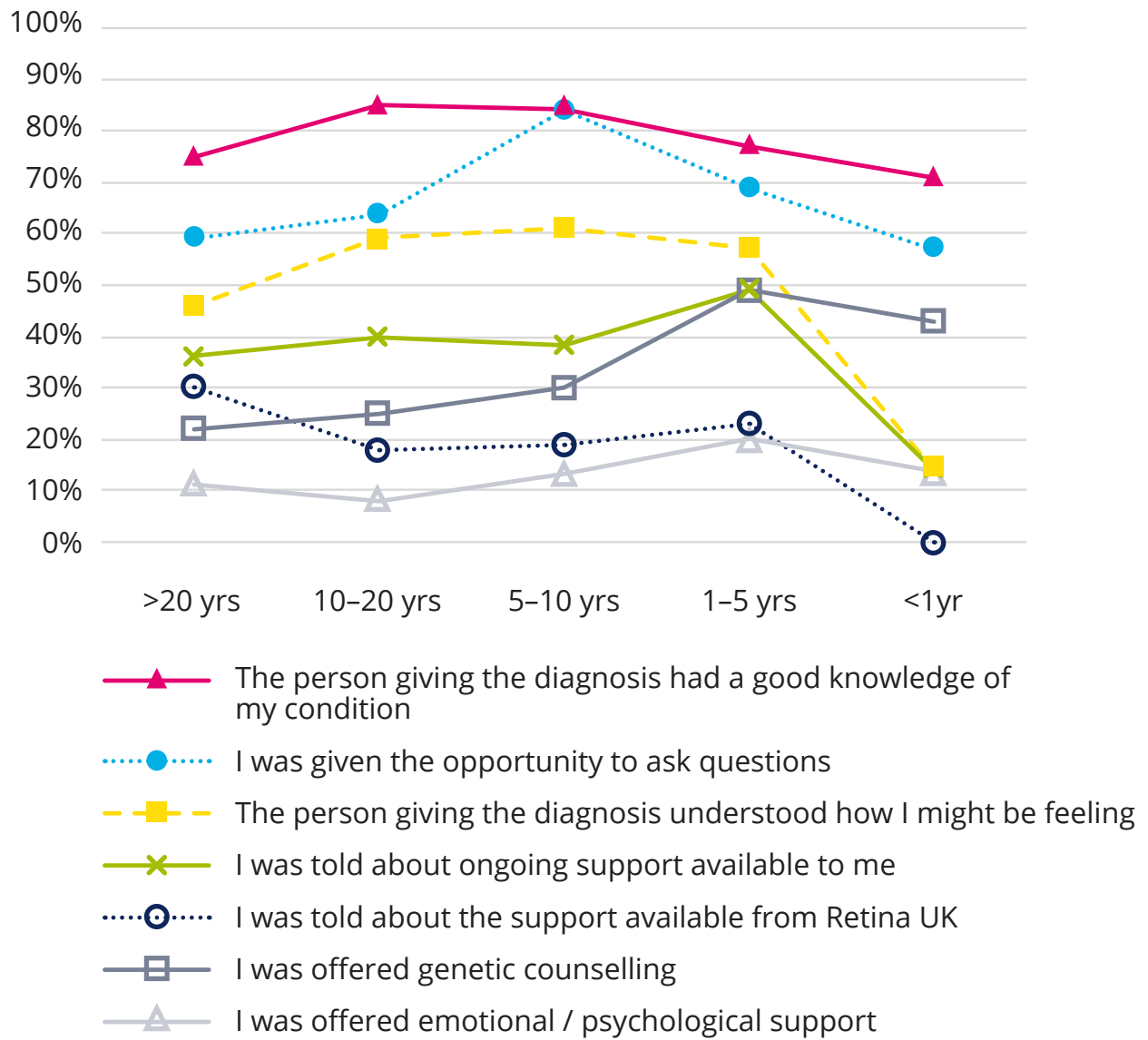
Those diagnosed in the past year reported a worse experience across all dimensions, in particular, in believing that the person giving the diagnosis understood how they might be feeling, and being told about ongoing support available to them. However, the number of respondents in this category was very small – fewer than 10.

A likely factor in the decline in quality of diagnosis is the pandemic, which has presumably reduced the likelihood of a timely diagnosis, or of significant face-to-face time with the person giving the news.

On the positive side, more than half of respondents, whenever they were diagnosed, said that the person giving the diagnosis had a good knowledge of their condition (78%), and that they were given the opportunity to ask questions (62%).

As in 2019, most respondents were not told about the support available from Retina UK (74% were not told, and 29% said they would have liked this).

EXPERIENCES OF DIAGNOSIS (ALL RESPONDENTS)





## SERVICES FOR PEOPLE WITH SIGHT LOSS

We asked respondents about their take-up of services available to people with sight loss, from social services support to genetic counselling, and the extent to which these made a positive difference to their lives. We've ranked services according to the biggest positive difference they make (totalling 'very' and 'some' positive difference scores from respondents who have accessed the service).

		Accessed	Positive difference
1	Advice on claiming benefits	62%	87%
2	Mobility training	54%	85%
3	Access to work scheme	41%	75%
4	Social services support	54%	68%
5=	Genetic testing	59%	65%
5=	Workplace occupational health support	40%	65%
5=	Counselling	25%	65%
8	Eye clinic and signposting (ECLO)	43%	60%
9	Genetic counselling	37%	50%
10	Support to change careers	20%	40%

The top three in this list hasn't changed since 2019, but there are some differences elsewhere. Satisfaction with social services support and genetic testing have increased, and access to the latter has also increased, to 59% respondents saying they've accessed this, compared with 46% in 2019.

We also asked about the barriers that prevented respondents accessing these services. In many cases, the specific service was not one they needed or wanted. However, respondents also told us they were not aware of some of these services, or that these services were not available to them.

		Accessed	Positive difference	Not aware or not available
1	Advice on claiming benefits	62%	87%	36%
2	Mobility training	54%	85%	34%
3	Access to work scheme	41%	75%	19%
4	Social services support	54%	68%	39%
5=	Genetic testing	59%	65%	54%
5=	Workplace occupational health support	40%	65%	21%
5=	Counselling	25%	65%	40%
8	Eye clinic and signposting (ECLO)	43%	60%	56%
9	Genetic counselling	37%	50%	49%
10	Support to change careers	20%	40%	25%

From this, we can extract the top five responses that respondents said they were unable to access, either because they didn't know about them, or because they were unavailable.

- 1** Eye clinic support and signposting (ECLO)
- 2** Genetic testing
- 3** Genetic counselling
- 4** Counselling
- 5** Social services support

Three of these services – genetic testing, counselling and social services support – appear within both top five lists: the services making the biggest positive difference for those who access them, and those that are hardest to access.

It's worth noting that while access to genetic testing appears to have improved since 2019, the unmet need has also increased.

## SUPPORT FROM PEOPLE AND GROUPS

People with sight loss also access charity, community and peer support. We asked which of these sources of support people 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 respondents who haven’t accessed this support.

	Accessed	Positive difference
A local sight loss organisation	54%	74%
Informal meetings with others affected	49%	74%
Other national sight loss charities	68%	73%
Retina UK staff or volunteers	60%	63%
Online sight loss community	39%	62%

The main difference from 2019 is in the role of local support – either through an organisation or via more informal channels. Both scored higher on positive difference compared with 2019: the score for local sight loss organisations rose from 66% to 74%.

Satisfaction with support from Retina UK staff and volunteers also improved slightly, from 58% in 2019 to 63% in 2022.

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
A local sight loss organisation	28%	18%
Informal meetings with others affected	29%	22%
Other national sight loss charities	25%	7%
Retina UK staff or volunteers	27%	13%
Online sight loss community	34%	27%

Compared with 2019, this set of respondents are less likely to feel they need access to online sight loss communities. This may be related to sampling.

## FALLS AND ACCIDENTS

Just over one third of respondents (39%) had experienced a fall or accident directly related to their sight loss condition, that had required outside support.

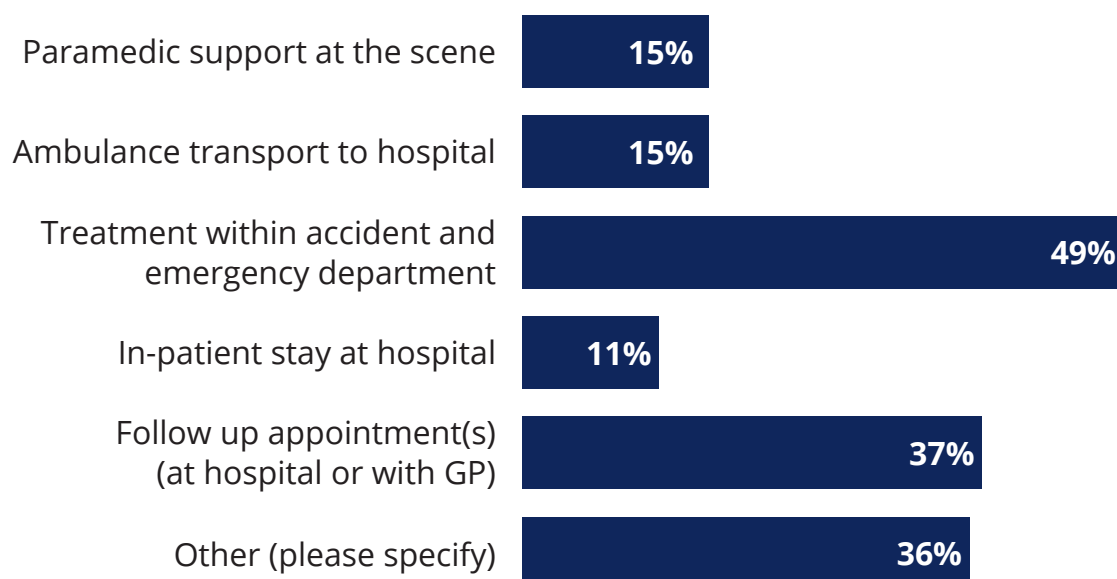
People who are sight loss registered were more likely to have experienced a fall or accident, compared to those not registered.

Half of those who had experienced a fall or accident ended up being treated in A&E (49%), and a third had a follow-up appointment with health services (37%). Around one in 10 cases ended up with paramedic support and/or ambulance transport to hospital (15% each).

Many respondents reported treating themselves or getting help from family, friends or neighbours. It sounds for some that minor injuries are a regular part of their experience, and they just 'get on with it'.

### FOLLOW-UP CARE (EXPERIENCED A FALL/ACCIDENT IN THE PAST 5 YEARS)

**Which of these did you need as a result of your fall(s) or accident(s)?  
Select all that apply.**



## AIDS, EQUIPMENT AND ASSISTIVE TECHNOLOGIES

Respondents access a wide range of aids, equipment and assistive technologies to help them manage life with sight loss. The most popular were:

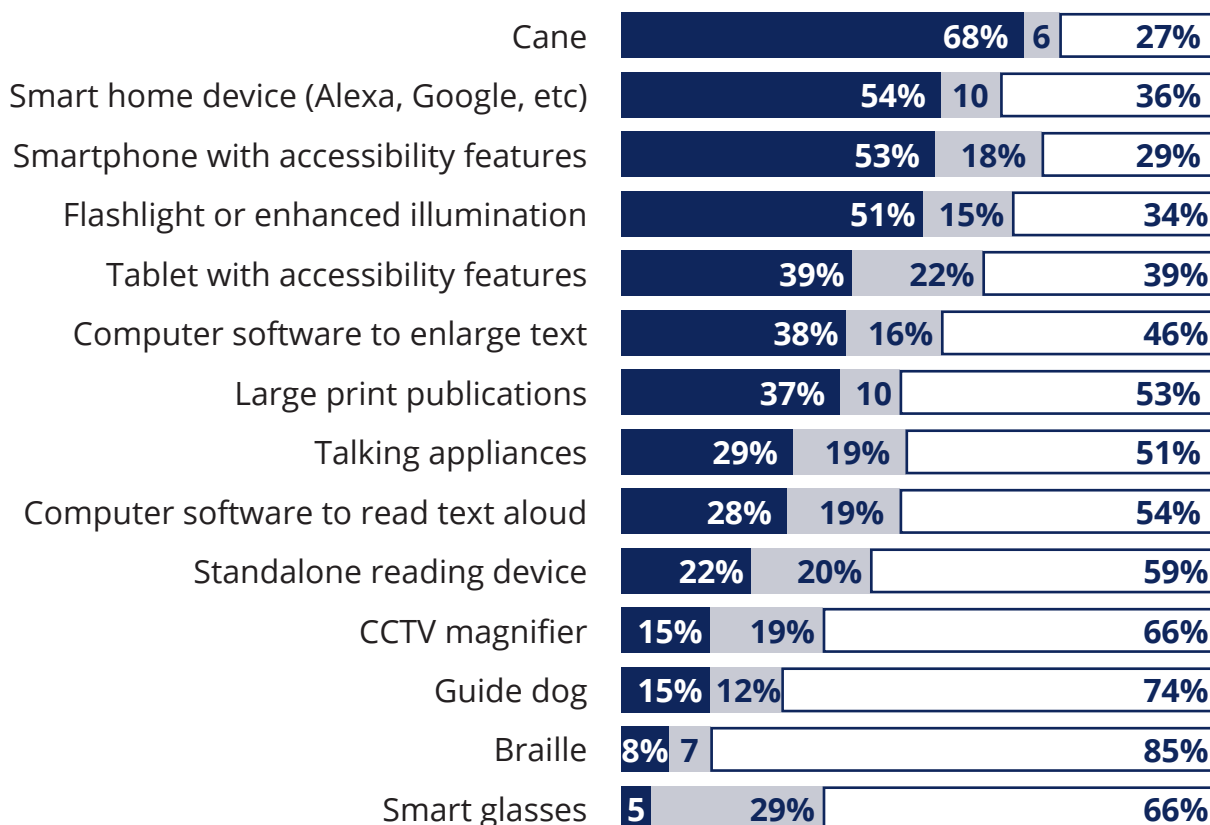
	<b>% using</b>
Cane	68%
Smart home device (Alexa, Google, etc)	54%
Smartphone with accessibility features	53%
Flashlight or enhanced illumination	51%
Tablet with accessibility features	39%
Computer software to enlarge text	39%

The big change from 2019 is the proportion of respondents using Alexa-style smart home devices (up from 33% to 54%), and to a lesser extent, smartphones with accessibility features (from 44% to 53%).

We also asked which equipment or aids respondents would like to use, but don't current. The top items tech devices or applications: smart glasses (29% would like to use this); followed by tablets with accessibility features (23%) and standalone reading devices (20%).

**USE OF AIDS, ASSISTIVE TECHNOLOGY OR COMMUNICATIONS SUPPORT  
(ALL RESPONDENTS)**

**Do you use any of these types of aids, assistive technology or communications support?**



Yes, I use this   
  No, but I would like this   
  No, I don't need this

Lack of knowledge of how to obtain items was the main barrier to access, followed by expense. Other barriers included not feeling confident to use particular aids, or not being aware of them in the first place.

Don't know how to obtain	37%
Too expensive	32%
Not confident to use	24%
Did not know it existed	21%
Told it is not suitable or available	8%
Other reason	27%

Reviewing ‘other’ reasons suggests some barriers are more psychological, as they link to people’s willingness to accept their degree of sight loss, or concerns about signalling this to others through the use of aids. Some respondents with Usher syndrome highlighted that the aids listed were not all appropriate to their needs.

### COMPARISON WITH 2019

The mostly positive upwards trend in people’s experience of diagnosis that we reported in 2019 appears to have been arrested, or even reversed. This may be related to the pandemic, and end up as a ‘blip’ in the long-term trend. However, it’s still the case that respondents are rarely signposted to Retina UK at the point of diagnosis – just as in 2019.

A larger proportion of respondents are accessing genetic testing, and experiencing a positive difference, compared with 2019. This is good news, though there’s an increasing unmet need in this area too.

Social services support also appears to have improved, compared with 2019.

There are signs of an increasing role for locally-based support – whether via a local organisation or more informal meet-ups. Again, this may be a response to pandemic restrictions.

A larger proportion of respondents are now using Alexa-style smart home devices, and accessibility features on their smartphones.

## 07 CLINICAL RESEARCH

### KEY FINDINGS

- More than half (54%) are aware of clinical research into their type of sight loss, and 20% have participated in research.
- Retina UK is the top source of research information. As in 2019, awareness of research is much higher among those who have engaged with Retina UK compared with those who haven't (59% compared with 38%).

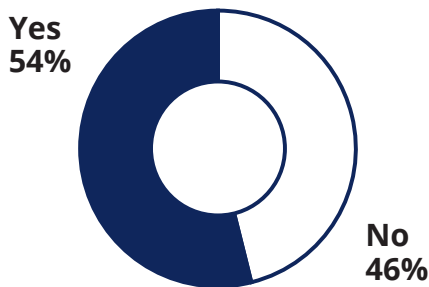
### AWARENESS OF CLINICAL RESEARCH

More than half of respondents (54%) were aware of clinical trials or other ongoing research into their type of sight loss.

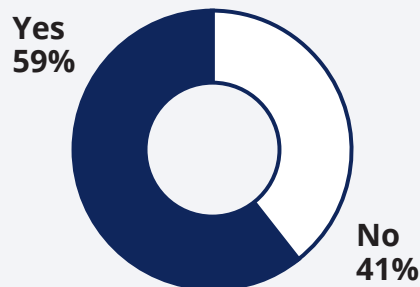
As in 2019, awareness of research was much higher among those who have engaged with Retina UK compared with those who haven't (59% compared with 38%).

### AWARENESS OF CLINICAL TRIALS OR OTHER RESEARCH

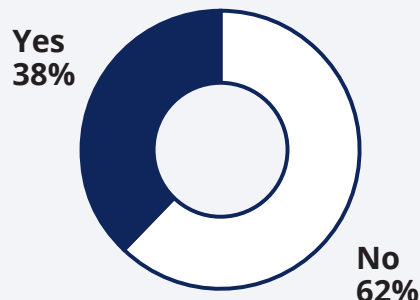
#### All respondents



#### Engaged with Retina UK



#### Not engaged with Retina UK





## SOURCES OF RESEARCH INFORMATION

Retina UK was the top source of research information for respondents, with more than two thirds (70%) of those who knew about research citing the charity as the source. Retina UK was more than twice as likely to be mentioned as the next highest source (ophthalmologist).

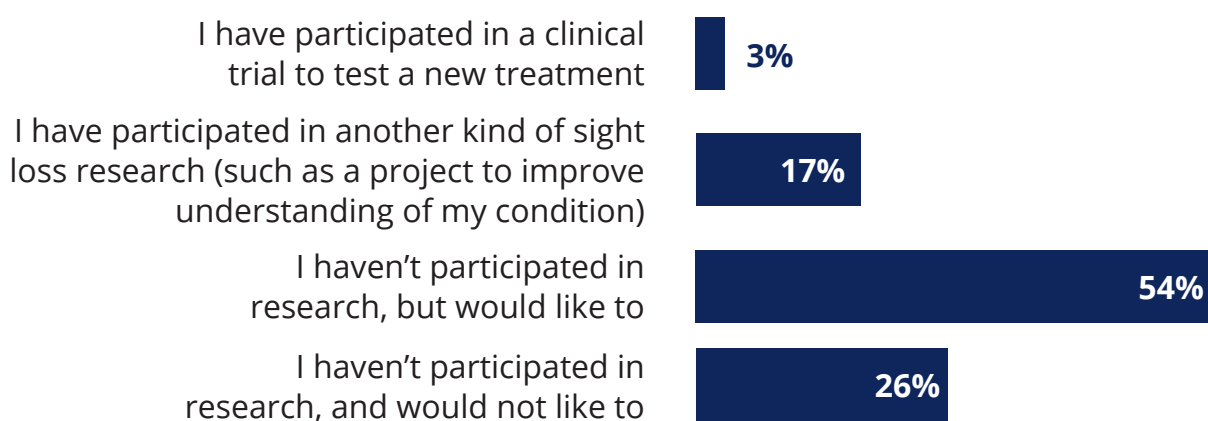
Retina UK	70%
Ophthalmologist (eye specialist)	27%
Web search	12%
A charity or patient group (not Retina UK)	10%
Online community	8%
Optometrist	3%
UK Clinical Trials Gateway website	2%
Clinicaltrials.gov website	2%
GP	1%

## RESEARCH EXPERIENCE AND INTEREST

Just over half of people (54%) would like to participate in a clinical trial or some other kind of research, but haven't yet. A further 20% have participated in research, and 26% say they do not want to. These percentages are very similar to 2019.

### EXPERIENCE OF CLINICAL TRIALS OR OTHER RESEARCH (ALL RESPONDENTS)

**Which of these statements best describes your experience of clinical trials or other research into your type of sight loss?**



## 08 MENTAL HEALTH

### KEY FINDINGS

- A relatively small percentage of respondents (16%) said they had accessed mental health support in relation to their sight loss. Of those who hadn't, 80% said it was because they were not in need of it.
- Of those who had received support, four in five had accessed a talking therapy such as counselling or psychotherapy. Two in five (41%) received prescription medication.
- Half had referred themselves, and a further third were referred by a health professional.
- Most benefited to some degree from their mental health support, though respondents were more likely to say it made managing 'somewhat' easier (56%), rather than 'much' easier (18%).

### MENTAL HEALTH SUPPORT NEEDS

A relatively small percentage (16%, fewer than one in five) of respondents said they had accessed mental health support in relation to their sight loss. Rates of access to mental health support were slightly lower among those diagnosed more than 20 years ago (14% compared with 16%), and those aged over 55 (10%).

Of those who hadn't, 80% said it was because they were not in need of it, and 5% said they would like it, but it was not available to them. This is despite 93% of all respondents reporting one or more emotional or psychological impacts resulting from their sight loss (page 16). It may be that many of those experiencing these impacts:

- are unaware that these are areas where mental health support could be beneficial

- feel able to manage these impacts without further support
- are reluctant to identify as being in need of support with their mental health

The proportion of people who have accessed mental health support is similar between those who say they're managing their sight loss and those who are not. However, among those not managing well, 12% say they would like mental health support but it is not available to them. That's more than double the percentage of all respondents (5%).

### ACCESS TO MENTAL HEALTH SUPPORT

Among those who have accessed mental health support:

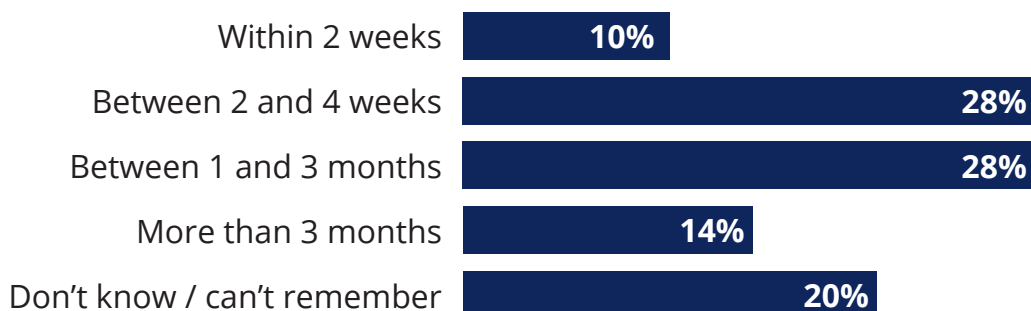
- 80% had accessed talking therapies
- 41% had received prescription medication
- 38% had used self-help resources, including peer support

Half had referred themselves (51%), and a further third (33%) had been referred by a health professional, such as a GP.

The most common time period to wait from seeking mental health support to receiving it was between two weeks and three months:

### 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.**

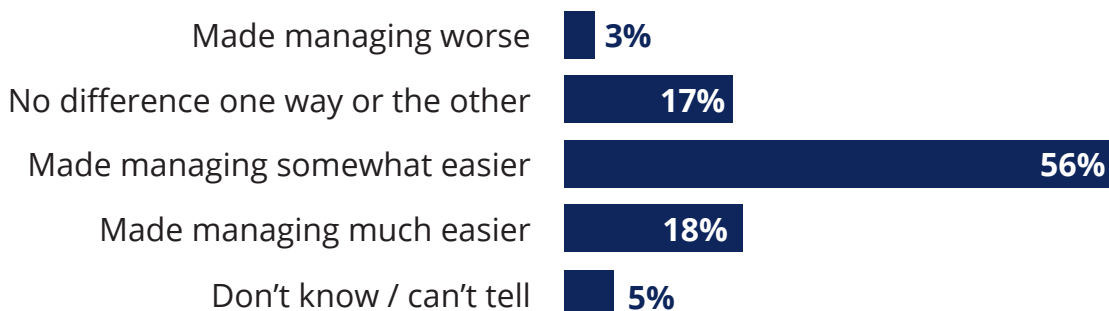


## IMPACT OF MENTAL HEALTH SUPPORT

Most respondents have experienced some level of positive benefit from the mental health support they had received: three quarters (74%) said it had made managing much easier (18%) or somewhat easier (56%).

But for one in five (20%), there was either no difference either way (17%), or the support they had received had made managing worse (3% - only three respondents).

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



## IMPACT OF MENTAL HEALTH SUPPORT

*'It's only recently that I've realised that I do need help with my mental health. The six years since diagnosis has been a state of denial about my sight loss.'*

*'Having counselling from someone with knowledge of disabilities (hearing and sight loss) is much more beneficial.'*

*'Mental health isn't just an issue for the person with RP, it can affect other family members ... No health professional has ever enquired about how my sight loss has impacted other members of my family. They are expected to cope, it would seem.'*

## 09 ATTITUDES TOWARDS RETINA UK

### KEY FINDINGS

- Those diagnosed more recently are most likely to have found about Retina UK from an internet search, while those diagnosed longer ago were signposted by a healthcare professional
- Eight in 10 (80%) have engaged with Retina UK in some way – a higher percentage than in 2019
- Engagement is higher among those: sight loss registered; diagnosed more than 20 years ago; diagnosed with RP; and who say they're managing their sight loss well
- Respondents mostly agree Retina UK is approachable, trustworthy and ambitious on behalf of people with sight loss. Compared with 2019, more agree people with sight loss have a big say in what the charity does.
- Almost nine in 10 (88%) agree that, thanks to Retina UK, they are better informed about ongoing research
- 83% rate Retina UK's service as 'excellent' or 'good'
- Newsletters achieve highest satisfaction and usage levels, followed by the website. There have been increases in satisfaction and take-up among many aspects of Retina's services, compared with 2019.
- More than half of respondents have donated or fundraised for Retina UK, with support levels higher among those diagnosed more than 20 years ago, and those managing their sight loss well
- Most people would like to see Retina UK focus mostly on research over the next three years, with the remainder equally split between wanting to see a focus on support provision and wanting to see a focus on improving societal understanding

## KNOWING ABOUT RETINA UK

Almost one in three people (30%) 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 relatively early days of the internet.

Those diagnosed more recently (within the past 20 years) are more likely to have found Retina UK via an internet search. This continues the significant shift seen in 2019, from people relying on word of mouth to know about Retina UK, to finding the charity through the internet.

Compared with 2019, a smaller proportion of respondents said they had not heard of Retina UK before this survey. This is likely to be related to a change in the way the survey was distributed.

The top ways people hear about us:

	All	Diagnosed up to 20 years ago	Diagnosed more than 20 years ago
From a healthcare professional	30%	20%	34%
Word of mouth	20%	14%	22%
Internet search	19%	35%	12%
From another charity or support group	11%	17%	9%
In the media	6%	4%	7%
Social media	2%	1%	2%
Not before this survey	2%	3%	1%

## ENGAGING WITH RETINA UK

Eight in ten (80%) of respondents said they had engaged with Retina UK in some way. This is higher than 2019 (70%), though this may relate in part to the change in the way the survey was distributed.

Those who have engaged did so through one or more of the following routes:

Member	54%
Access info and/or support	45%
Donate or raise funds	44%
Belong to Local Group	8%
Volunteer	5%
Paid staff member	<1%
None of these	19%

Compared with 2019, there's much more likelihood of respondents having engaged with Retina UK's info and support (45% vs 31%) and of having donated or raised funds (44% vs 30%).

And as in 2019, the following groups were more likely than others to have engaged with Retina UK:

- Respondents who are sight loss registered, compared with those not registered (82% compared with 76%)
- Respondents diagnosed more than 20 years ago, compared with those diagnosed since then (83% compared with 76%)
- Respondents diagnosed with RP (retinitis pigmentosa), compared with those with other diagnoses (86% compared with 70%)
- Those who say they are currently managing their sight loss well, compared with those who say they are not managing well (83% compared with 75%)

## PERCEPTIONS OF RETINA UK

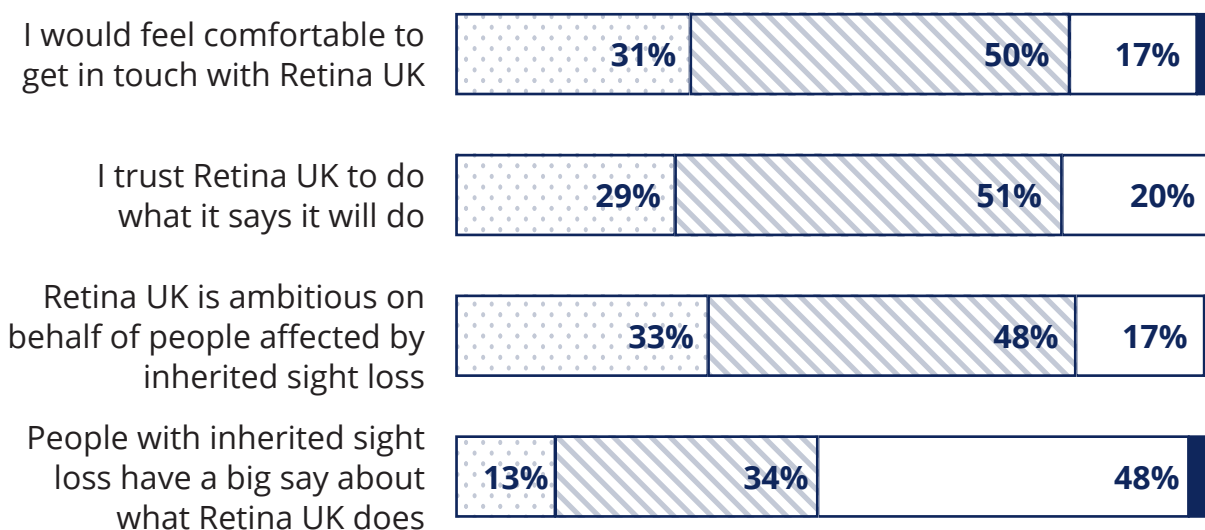
Respondents were mostly happy to agree Retina UK behaves in line with the charity’s values: that it’s approachable, ambitious and trustworthy.

Compared with 2019, there is a small increase in the proportion of people who agree that ‘people with inherited sight loss have a big say about what Retina UK does’ – from 42% to 47%. That still leaves around half (48%, same as in 2019) who are neutral on this.

Very few people disagree that Retina UK’s actions reflect its values – with significant proportions unsure one way or the other.

### BELIEFS ABOUT RETINA UK (ALL RESPONDENTS)

How far do you agree with each of these statements about Retina UK?



- Agree strongly
- Agree
- Neither agree nor disagree
- Disagree
- Disagree strongly



## THE DIFFERENCE RETINA UK MAKES

Almost nine in 10 respondents (88%) agreed that, thanks to Retina UK, they are ‘better informed about ongoing research’. This is a slight increase on 2019. Agreement is slightly higher among those diagnosed more than 20 years ago, compared with those diagnosed since then, and among those who are sight loss registered compared with those who are not.

Half (50%) agreed that Retina UK helps them have ‘greater awareness of the support available to me’. Again, this is a small increase on 2019 (45%).

One in four (20%) agreed that, thanks to Retina UK, they have ‘more confidence in managing the challenges of sight loss’. This is the same as in 2019.

Finally, one in 10 (10%) agreed that, thanks to Retina UK, they are ‘more able to lead a fulfilling life’. This is slightly higher than 2019 (7%) but considerably lower than the other outcome statements. In 2019 we speculated that this may be because a ‘fulfilling life’ is perhaps too abstract a concept for people to feel able to evaluate – this may still be the case.

## WHAT DIFFERENCE DOES RETINA UK MAKE TO YOU? (ALL RESPONDENTS)



## RETINA UK INFORMATION, SUPPORT AND SERVICES

Satisfaction with Retina UK’s information, support and services is high overall, and very much in line with 2019’s findings. Over four in five (83%) rate these services as ‘excellent’ (29%) or ‘good’ (54%). Only 3% said services were ‘not very’ or ‘not at all’ good – the same as in 2019.

### RATING INFORMATION, SUPPORT AND SERVICES FROM RETINA UK (USERS OF SERVICES ONLY)



Satisfaction (total of ‘very’ and ‘quite’ satisfied) was highest with online support: Facebook support groups, webinars, and the Retina UK website. There appear to be opportunities to broaden access to aspects of Retina UK support that are well-received, so that more people benefit from them.

	Accessed	Satisfied
Webinars	12%	99%
Regular newsletters	81%	96%
Website	52%	96%
Information days	27%	95%
Facebook support groups	19%	95%
Support with fundraising	20%	94%
Annual conference	21%	93%
Helpline	26%	92%
Local groups (online and face to face)	21%	87%
Telephone befriending service	5%	83%
Info for children & young people	3%	79%

Compared with 2019, there have been increases in take-up and satisfaction, particularly with:

- Local groups (including online communities) where usage is up from 18% to 21%, and satisfaction from 73% to 87%
- Retina UK's telephone befriending service, where satisfaction has increased significantly (from 73% in 2019 to 83% in 2022). However, this is still only accessed by a small proportion of respondents (5%).
- Information days, where take-up and satisfaction have both increased slightly
- The annual conference, accessed by 21% compared with 16% in 2019
- The helpline, where satisfaction has increased from 87% to 92%
- Support with fundraising, where satisfaction has increased from 86% to 94%

### **SUPPORTING RETINA UK**

Almost three in four respondents (72%) have supported Retina UK through donations or fundraising. Propensity to support Retina UK is higher among:

- Those diagnosed more than 20 years ago, compared with those diagnosed more recently (79% compared with 57%).
- Those who say they're managing well, compared with those who say they're not (76% compared with 67%)

When asked to say more about why they do or don't support Retina UK, there were a range of responses.

From some who have supported Retina UK:

*'Because I know what it feels like to be diagnosed with vision loss and I want there to be help out there for people.'*

*'To save my eyesight.'*

*'To try and make a difference and encourage more research and trials.'*

*'Retina UK is the only sight loss research organisation I have found which genuinely engages the community, keeps them updated and is transparent about the research funded.'*

From some who haven't:

*'I am busy with work, plus I don't have much of a social group so raising money is hard.'*

*'Can't afford it at the moment.'*

*'I would like to support through fundraising, but would need encouragement and guidance on how to do it.'*

### **RETINA UK'S FUTURE DIRECTION**

Respondents were asked 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 (56%) said the focus should be on 'funding and promoting the search for causes and treatments for inherited sight loss'.

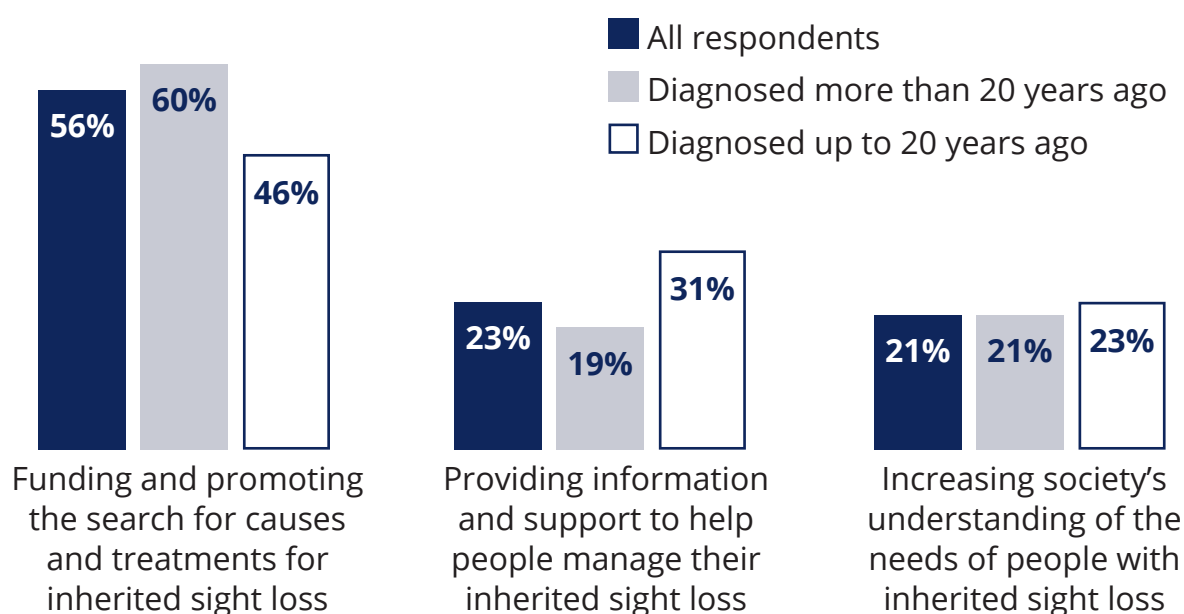
The remainder were split more or less equally between 'providing information and support to help people manage their inherited sight loss' (23%), and 'increasing society's understanding of the needs of people with inherited sight loss' (21%).

People diagnosed more than 20 years ago were more likely to select a research focus, compared with those diagnosed more recently (60% compared with 45%). This is also true of those aged over 55 (also 60%).

While all groups prioritised research, there were some that put more emphasis on information and support than on increasing society's understanding of sight loss:

- Those diagnosed less than 20 years ago
- Those not sight loss registered
- Those who say they're not managing their sight loss well

**WHAT SHOULD RETINA UK CONCENTRATE OUR EFFORTS ON MOST OVER THE NEXT THREE YEARS?**



**COMPARISON WITH 2019**

The overall picture with regards to attitudes to Retina UK is a positive one, with increases across a range of measures of engagement and satisfaction, compared with 2019.

We saw elsewhere in the survey that there was a greater interest in support at a local or community-based level, and this is reflected in the increased take-up and satisfaction with local groups, including online communities.



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