



# Sight loss survey 2019

Findings from our survey of more than 900 people living with inherited sight loss.

Research by Retina UK in partnership with Self Comms.

June 2019



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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. Our vision is a world where everyone with inherited sight loss is able to live a fulfilling life. To fulfil this vision we have two objectives; 1) Stimulate and fund medical research to increase the understanding of inherited retinal conditions and accelerate the search for treatments for the future and 2) Provide information and support to help people lead better lives, today. We ensure no-one with inherited sight loss need feel alone.

We are an organisation entirely focussed on people living with inherited retinal dystrophies; to make the biggest difference for our community and fulfil our objectives we needed to learn more about real-life experiences, challenges and expectations.

Thank you to everyone who completed our survey. These findings will inform, influence and guide Retina UK to even better achieve our vision in the future. We are delighted to share this piece of insight with you and hope that it has the same benefits for you and/or your organisation.

Tina Houlihan  
Chief Executive  
Retina UK

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# Introduction

Retina UK wanted to undertake a comprehensive survey of the experiences of people with inherited sight loss. The aim was to better understand people's views and experiences, and use this knowledge to guide future plans. This report draws together the findings of this survey.

## About the survey

Retina UK partnered with Self Comms, a communications consultancy experienced in gathering actionable audience insight for charities and non-profits, to conduct this survey.

We identified the topics we wanted to know about most, and designed a questionnaire that could be completed by anyone living with inherited sight loss (or by their parent or guardian if they were aged 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 based on their feedback. The questionnaire covered:

- Demographic information
- Sight loss condition
- Quality of life
- Access to and satisfaction with services and support
- Knowledge of and participation in clinical research
- Engagement with Retina UK

The questionnaire was made available for online completion and as a printed booklet. Fieldwork took place between mid-March and early May 2019. Retina UK promoted the survey widely, including through its own communication channels and via health professionals and online communities. The charity provided volunteer assistance to those who may otherwise have struggled to complete the questionnaire.

In total we received 924 responses.

# Summary of key findings

- Most respondents (84%) are registered as sight impaired or severely sight impaired. Three in four (74%) have been diagnosed with RP (retinitis pigmentosa), and almost two thirds (61%) were diagnosed over 20 years ago. Around 15% know the gene implicated in their condition.
- Over half (53%) say their sight loss has a severe or very severe impact on their quality of life.
- Two in three (69%) say they're managing their sight loss well, compared with 27% who say they want to be able to manage it better. Those who say they're managing well are more likely to have engaged with Retina UK.
- Loss of confidence, anxiety and stress are the biggest emotional or psychological impacts of sight loss. Only 8% say they've experienced no impacts like these.
- Those who have engaged with Retina UK are less likely to say they've experienced isolation or loneliness, compared with those who have not engaged.
- Sight loss particularly impacts on: mobility and getting around; leisure time and hobbies; and social life.
- The experience of being diagnosed has improved over the past 20 years. But only around one in five are told about support available from Retina UK, and this is not changing.

- Almost two in three respondents (63%) receive ongoing care from an ophthalmologist, and most (77%) are satisfied with the care they receive.
- The most useful services are: benefits advice; mobility training; access to work schemes; and counselling. Benefits advice and counselling also appear on the list of services hardest to access, either because people don't know about them, or because they are not available.
- Beyond formal services, respondents benefit from informal meetings with others affected by sight loss, and support from other national sight loss charities.
- Respondents access a wide range of aids, but many would like to access more assistive technologies such as devices and apps.
- More than half (58%) 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, and awareness of research is much higher among those who have engaged with us (65%, compared with 48% of those who haven't engaged). Four in five (81%) agree that, thanks to Retina UK, they are better informed about ongoing research.
- Respondents mostly agree Retina UK is approachable, trustworthy, and ambitious on behalf of people with sight loss. They are less likely to agree people with sight loss have a big say in what Retina UK does. 80% rate our services as 'excellent' or 'good'.



# About the respondents

Of the 924 individuals who responded:

- 92% completed the survey on their own behalf, and 8% were the parent/guardian responding on behalf of a child aged under 18.
- Just over half identified as female (54%) and just under half as male (44%).
- 93% were white, 5% were from an Asian or mixed Asian background, and the remainder were from other ethnic backgrounds.
- The age range was as follows:

Under 18	4%
18-25	3%
26-35	4%
36-45	11%
46-55	20%
56-65	22%
66-75	21%
Over 75	16%

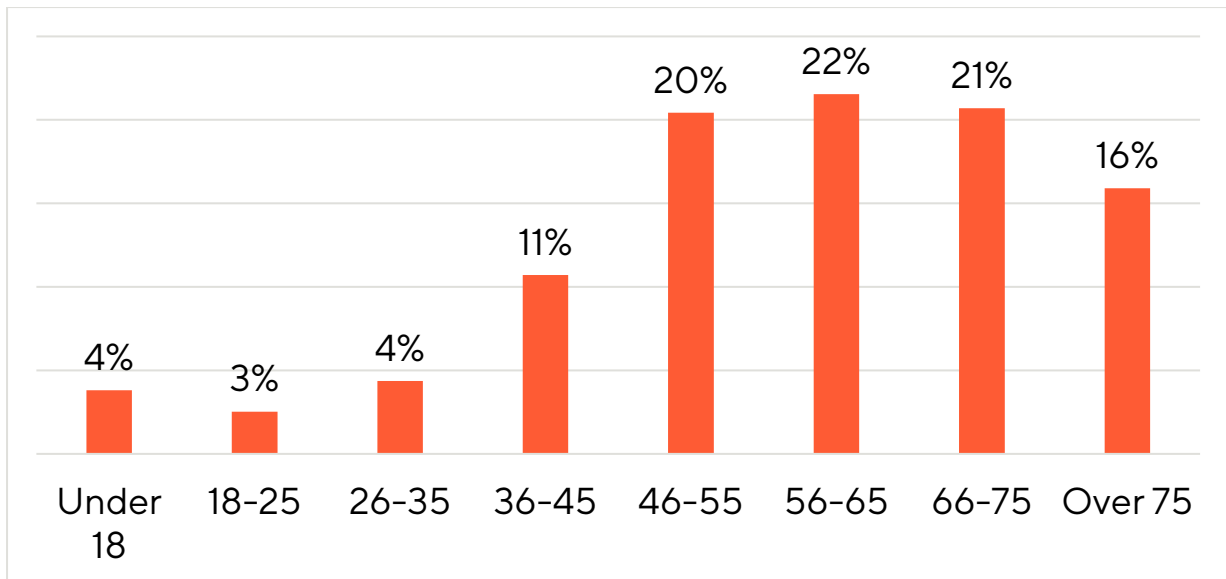


Figure 1: Respondent ages (all respondents)

- 45% were retired, 18% in full time employment and 16% not in paid work:

Retired	45%
Employed full time	18%
Not in paid work	16%
Doing voluntary work	9%
Employed part time (working 30 hours or less)	8%
In full or part-time education or training	6%
Self-employed part time	3%
Self-employed full time	3%
Other (please specify)	7%

### 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:

<p>Sight loss registered (84%)</p> <p>Q: Are you registered as severely sight impaired or sight impaired?</p> <p>Responded:  <i>Yes, I am registered as severely sight impaired or</i>  <i>Yes, I am registered as sight impaired</i></p>	<p>Not registered (16%)</p> <p>Q: Are you registered as severely sight impaired or sight impaired?</p> <p>Responded:  <i>No, my degree of sight loss does not meet the criteria or</i>  <i>No, I have chosen not to be registered</i></p>
<p>Diagnosed less than 20 years ago (39%)</p> <p>Q: How long ago were you diagnosed with your sight condition?</p> <p>Responded with one of:  <i>Within the past 12 months</i>  <i>Between 1 and 5 years ago</i>  <i>Between 5 and 10 years ago</i>  <i>Between 10 and 20 years ago</i></p>	<p>Diagnosed more than 20 years ago (61%)</p> <p>Q: How long ago were you diagnosed with your sight condition?</p> <p>Responded:  <i>More than 20 years ago</i></p>

<p>Currently managing well (69%)*</p> <p>Q: Which of these statements best describes your current situation?</p> <p>Responded:  <i>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.</i></p>	<p>Not currently managing well (25%)*</p> <p>Q: Which of these statements best describes your current situation?</p> <p>Responded:  <i>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.</i></p>
<p>Have engaged with Retina UK (70%)</p> <p>Q: Here are some ways people get involved with Retina UK. Which of them apply to you?</p> <p>Responded with one or more of:  <i>I access information and/or support</i>  <i>I am a member</i>  <i>I belong to a Local Group</i>  <i>I donate or raise funds</i>  <i>I am a volunteer</i>  <i>I am a paid member of staff</i></p>	<p>Have not engaged with Retina UK (30%)</p> <p>Q: Here are some ways people get involved with Retina UK. Which of them apply to you?</p> <p>Responded with:  <i>None of these</i></p>

\*These two percentages do not add up to 100%, as we've omitted the 6% of respondents who selected a third option to this question: *'I'm recently diagnosed, and still adjusting to life with sight loss.'*

# Types of sight loss

## Key findings

- Most respondents (84%) are sight loss registered.
- Three in four (74%) have been diagnosed with RP (retinitis pigmentosa).
- Almost two thirds (61%) were diagnosed over 20 years ago.
- Around 15% know the name of the gene, or genetic variant, implicated in their condition.
- 9% have no vision at all, and 7% have good overall vision.

## Sight loss registration

Most respondents (84%) were either registered as sight impaired (19%) or severely sight impaired (65%). Of those not registered, 9% said their degree of sight loss did not meet the criteria for registration, and 6% said they had chosen not be registered.

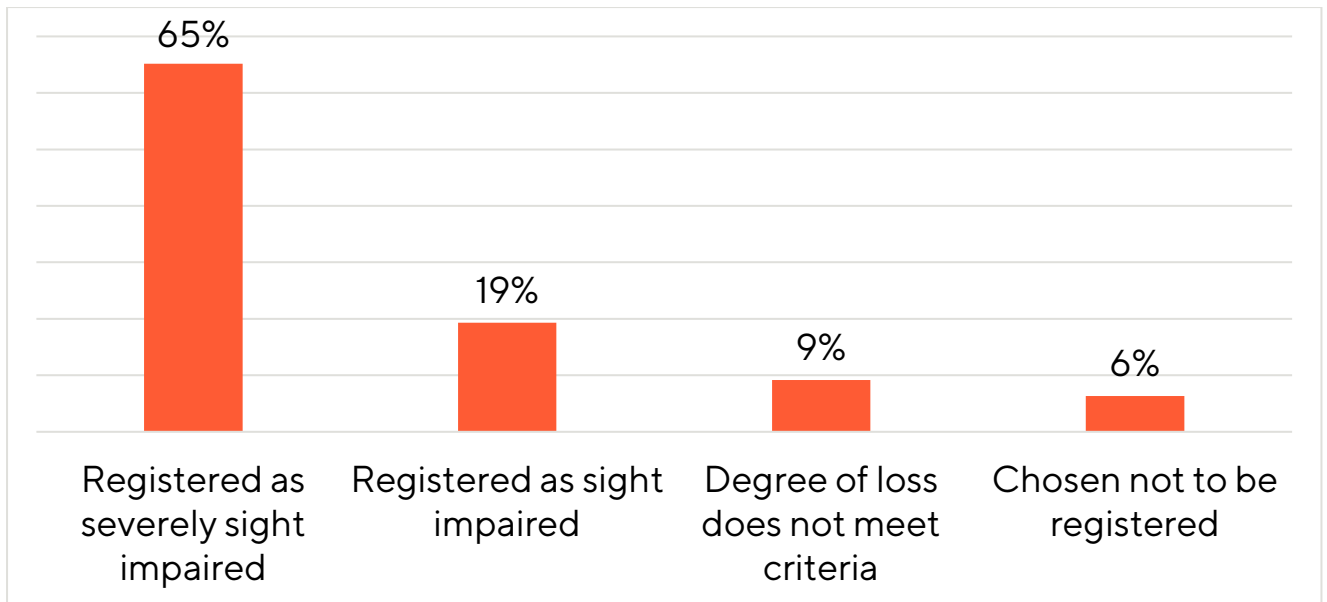


Figure 2: Q1 Are you registered as severely sight impaired or sight impaired? (all respondents)

### Diagnosed condition

Almost three out of four respondents (74%) had been diagnosed with RP (retinitis pigmentosa). The remaining 21% had a range of other conditions. The most frequently mentioned were Usher Syndrome (8%) and Stargardt disease (2%).

Classic retinitis pigmentosa (RP)	74%
Usher syndrome	8%
Stargardt disease	2%
Cone-rod dystrophy	2%
Rod-cone dystrophy	2%
Choroideremia	1%
Bardot-Biedl syndrome	1%
Leber congenital amaurosis	1%
Macular degeneration	1%
Nystagmus	1%

## Genetic diagnosis

Just over four in 10 (41%) of respondents said they had received a genetic diagnosis for their sight condition.

But analysis of their free text responses shows only 15% were able to provide the name of a gene or specific type of RP (which correlates to a specific gene).

Of those who said they've received a genetic diagnosis, but didn't provide a recognisable gene / genetic disease type:

- A small number said they had forgotten it.
- Some said they'd had genetic testing but a specific gene had not been identified.
- Some described an inheritance pattern.

*"I had guessed I had RP because of my Mum's severe sight loss but it was still a shock. I am lucky at the moment because it is only in poor light that I struggle, but I know it is getting worse."*

## Time since diagnosis

More than six in 10 respondents (61%) were diagnosed over 20 years ago:

Past 12 months	2%
1 - 5 years ago	7%
5 - 10 years ago	10%
10 - 20 years ago	20%
Over 20 years ago	61%

Those diagnosed more than 20 years ago were more likely to be sight

loss registered, compared with those diagnosed less than 20 years ago (93% compared with 73%).

## Remaining vision

Respondents reported different degrees and types of remaining vision. Almost one in 10 (9%) had no vision at all, while 7% had good overall vision. Many of those who answered 'other' said they experienced loss of good vision only at night, or only in one eye.

No vision	9%
Light perception / shadows only	17%
Some useful central vision	41%
Good central vision	24%
Some useful peripheral vision	16%
Good peripheral vision	3%
Good overall vision	7%
Other	9%



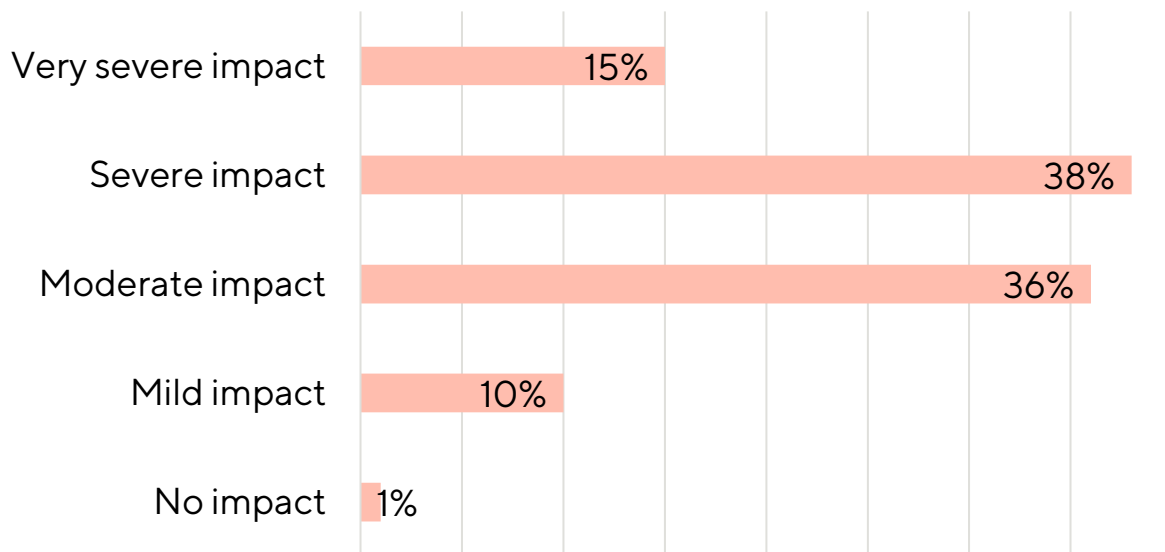
# Quality of life

## Key findings

- Over half of respondents (53%) say their sight loss has a severe or very severe impact on their quality of life.
- Two in three (69%) say they're managing their sight loss well, compared with 27% who say they want to be able to manage it better. Those who say they're managing well are more likely to have engaged with Retina UK.
- Loss of confidence, anxiety and stress are the biggest emotional or psychological impacts of sight loss. Only 8% say they've experienced no impacts like these.
- Those who have engaged with Retina UK are less likely to say they've experienced isolation or loneliness, 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

Over half of respondents (53%) said their sight loss had a severe or very severe impact on their quality of life.



*Figure 3: Q6 Right now, what impact does your sight condition have on your quality of life overall? (all respondents)*

Those diagnosed over 20 years ago were almost twice as likely to say the impact on their quality of life was severe or very severe, compared with those diagnosed since (64% compared with 34%).

Those who are sight loss registered were also more likely to say their sight loss had a severe or very severe impact on their quality of life – 85% said this, compared with only 13% of those not registered.

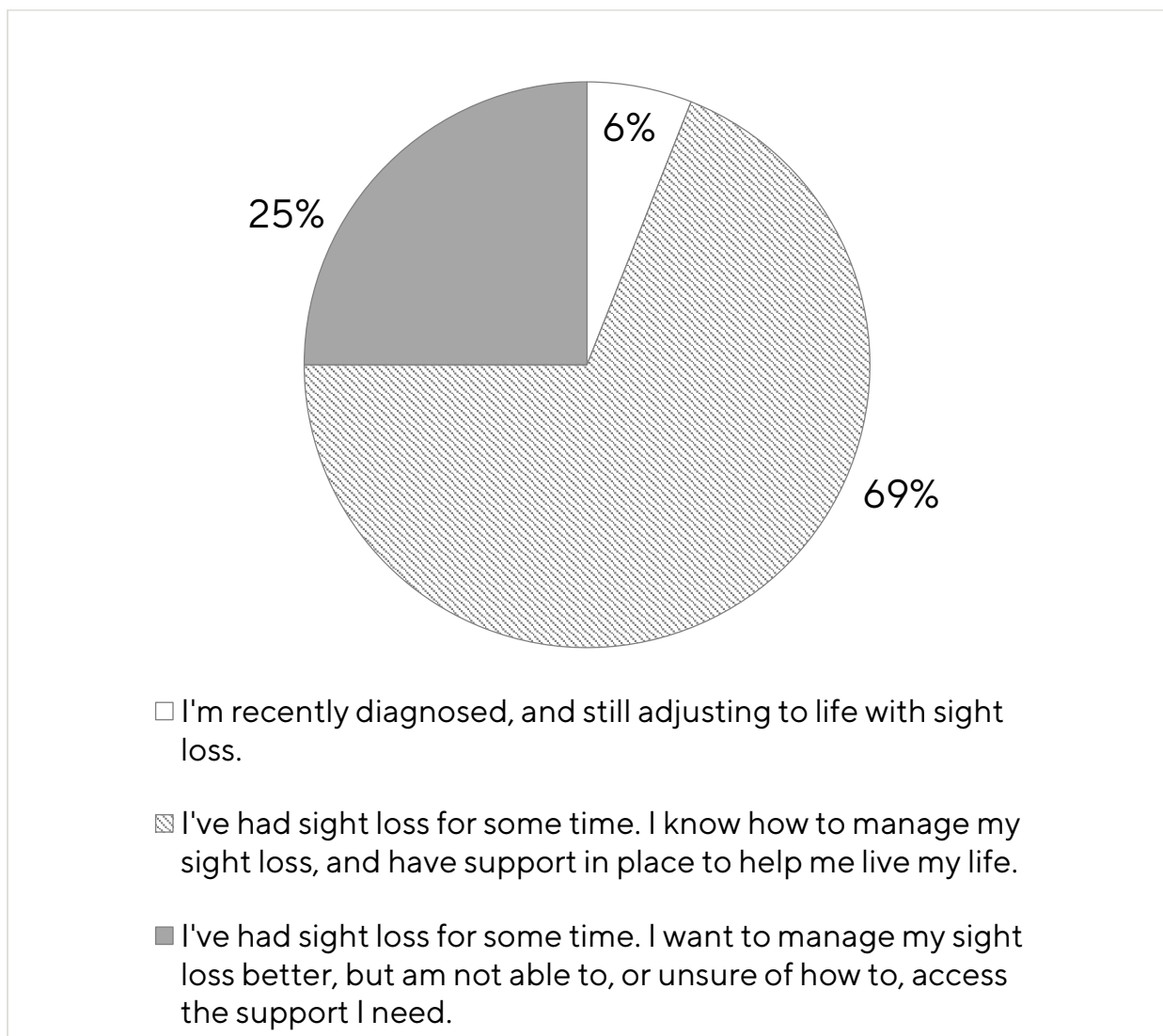
*“Living with degenerative sight loss is relentlessly challenging. Ongoing emotional support and specialist counselling should be available at all stages.”*

## **Managing the impact of sight loss**

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

- 6% agreed: ‘I am recently diagnosed, and still adjusting to life with sight loss.’

- 69% 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.'
- 25% 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.'



*Figure 4: Q7 Which of these statements best describes your current situation? (all respondents)*

Two thirds (68%) of those who said they are managing well were diagnosed with sight loss more than 20 years ago, compared with only 57% of those who say they're not managing well.

Those who say they're managing their sight loss well are more likely to have engaged with Retina UK, compared with those who say they are not managing well (73% compared with 61%).

*"My son has been amazing at coping with his diagnosis – very determined, enjoying his life and refuses to let it get him down. I am full of admiration for him. As his mum, I have not coped so well and am very worried about his future, especially around employment."*

## 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:

Loss of confidence	72%
Anxiety	71%
Stress	62%
Fear	54%
Anger	44%

Only 8% said they'd experienced no emotional or psychological impacts.

*"I am a very private person, but feel totally lost and unsupported and fearful for the future – for my career, my young family and for my independence."*

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

- 33% of those who have engaged with Retina UK said they experienced isolation, compared with 45% of those who have not engaged.
- 31% reported loneliness, compared with 41% of those 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'. Ranked responses show the biggest impact people experience is connected with mobility and getting around, following by leisure time and hobbies:

	Affected to any degree	Impact is 'significant' or 'extreme'
Mobility and getting around	97%	64%
Leisure time and hobbies	94%	58%
Social life	91%	46%
Career / job	77%	47%
Day-to-day routines	92%	33%
Falls or accidents	90%	30%
Communication	75%	29%
Relationships	71%	24%
Family life	73%	22%
Education	55%	21%

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 (66% of those not managing well say this is 'significantly' or 'extremely' affected, compared with 39% of those managing well)
- Day-to-day routines (47% compared with 31%)
- Falls or accidents (47% compared with 26%)
- Relationships (41% compared with 20%)
- Education (34% compared with 17%)

*“Everyday tasks and routines have become much more of a challenge and most things require a lot more planning and time.”*

# Services and support

## Key findings

- People's experience of receiving their diagnosis has improved over the past 20 years.
- Despite this, only around one in five are told about the support available from Retina UK, and this has not improved over time.
- Almost two in three respondents (63%) have ongoing care from an ophthalmologist, and most (77%) are satisfied with the care they receive.
- The most useful services for people with sight loss are benefits advice; mobility training; access to work schemes; and counselling. Benefits advice and counselling also appear on the list of services hardest to access, either because people don't know about them, or because they are not available.
- Support via informal meetings with others affected by sight loss, and that provided by other national sight loss charities, make the biggest positive difference.
- Respondents access a wide range of aids, but many would like to access more assistive technologies such as devices and apps. The two main barriers are not knowing how to obtain these, and cost.

## Diagnosis

People's experience of receiving their diagnosis appears to have improved over the past 20 years. The biggest positive changes are in the percentages of respondents being offered genetic counselling, and in those feeling they are able to ask questions.

However, most respondents are still not told about the support available from Retina UK – and there is little sign that this has changed much over the past two decades.

And while the proportion of people being offered emotional or psychological support has risen (from 7% to 23%), it is still low overall.

*“The specialist who diagnosed me offered no support or information, I hadn't even heard of RP. I was just told that I would eventually go blind.”  
(Respondent diagnosed over 20 years ago)*

*“I should have received counselling. I was just left to get on with things. It has taken me years to come to terms with it all. It has been a very difficult journey. I hope things are much better now and people are given greater support and understanding.”*



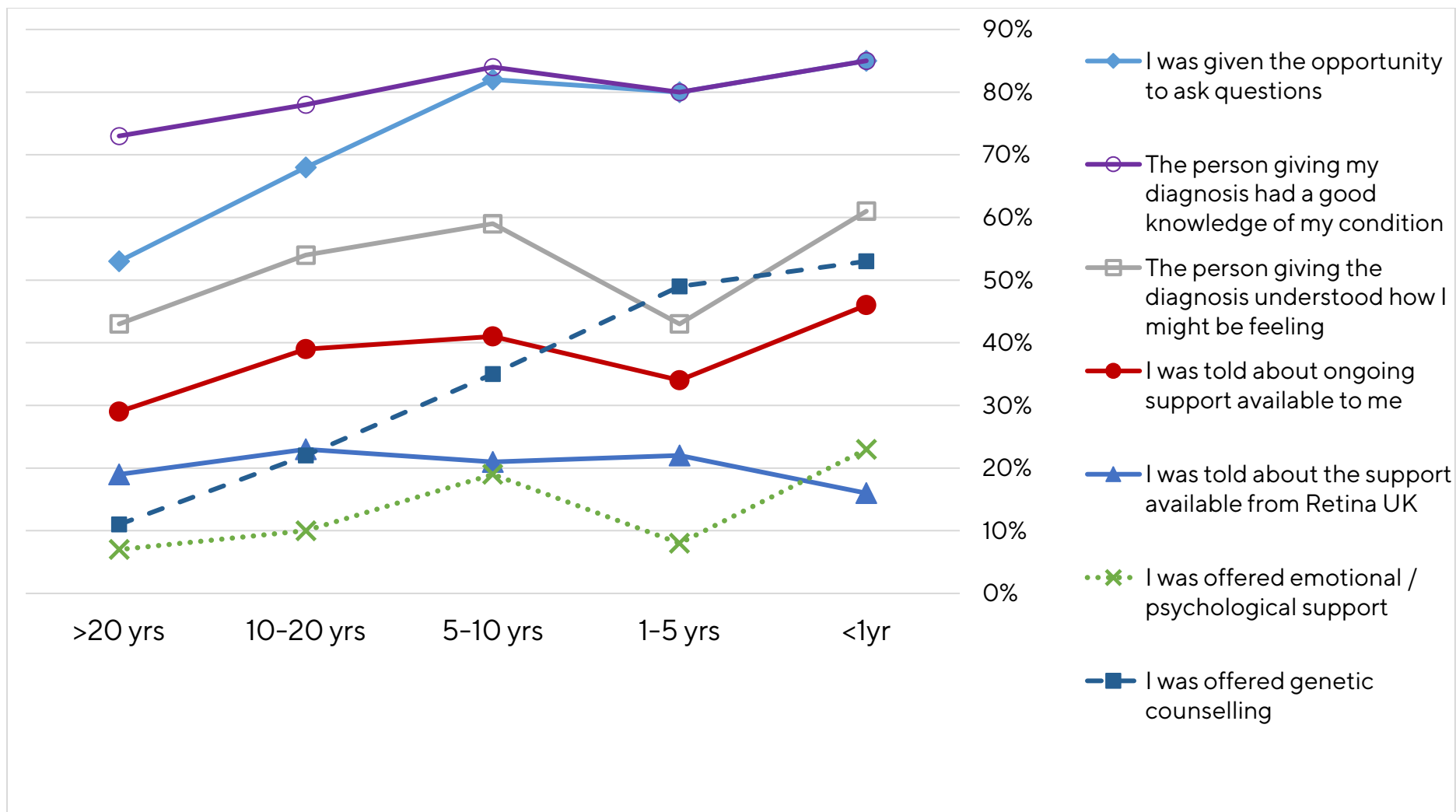
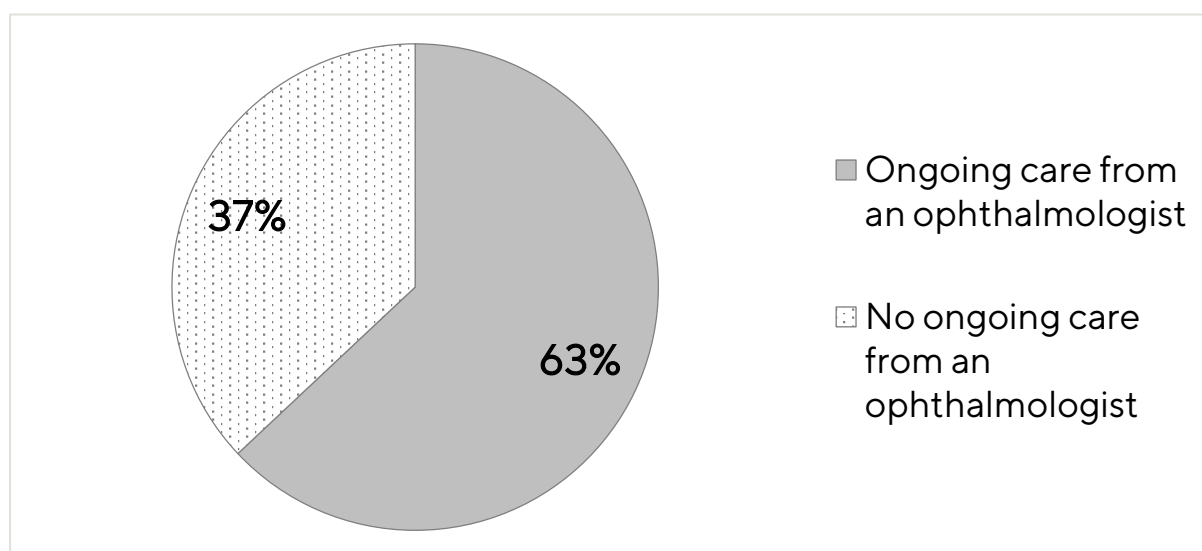


Figure 5: Q10 Thinking back to when you received your diagnosis... please select the relevant box for each statement (all respondents)

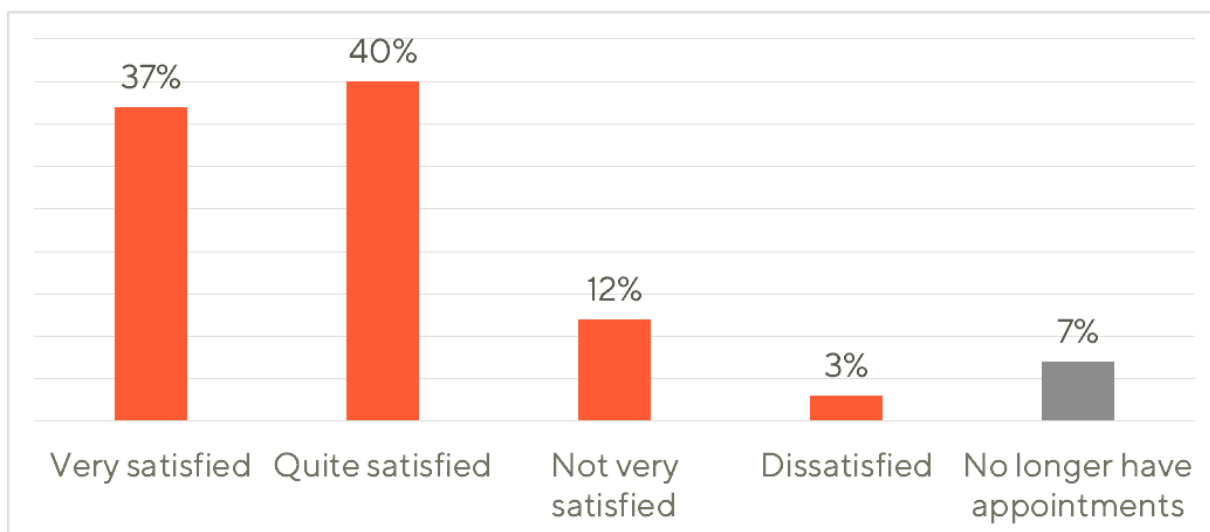
## Ongoing specialist eye care

Almost two in three respondents (63%) receive ongoing care from an ophthalmologist (specialist eye doctor). This rises to three in four (74%) of those diagnosed within the past 20 years.



*Figure 6: Q12 Do you have an ophthalmologist (specialist eye doctor) involved in your ongoing care? (all respondents)*

Overall satisfaction with the care provided by ophthalmologist is fairly high at 77% (the proportion of respondents who said they were 'very' or 'quite' satisfied). Satisfaction is somewhat higher among those diagnosed more than 20 years ago (80%) compared with those diagnosed since then (73%).



*Figure 7: Q13 How satisfied are you with the ongoing care you receive from your ophthalmologist? (respondents with an ophthalmologist involved in their ongoing care only)*

*"I have seen a different Doctor every single time I've had an appointment with ophthalmology. Feels like there is no continuity of care."*

## **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' + 'some' positive difference scores, excluding respondents who haven't accessed this service).

		Accessed	Positive difference
1	Advice on claiming benefits	57%	84%
2	Mobility training	48%	78%
3	Access to work scheme	31%	71%
4	Counselling	17%	61%
5	Workplace occupational health support	26%	58%
6	Social services support	50%	56%
7	Eye clinic support and signposting (ECLO)	31%	54%
8	Genetic counselling	29%	42%
9	Genetic testing	46%	39%
10	Support to change careers	12%	33%

We also asked about the barriers that prevented respondents accessing these services. In many cases, the service specified 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	57%	84%	41%
2	Mobility training	48%	78%	36%
3	Access to work scheme	31%	71%	30%
4	Counselling	17%	61%	46%
5	Workplace occupational health support	26%	58%	51%
6	Social services support	50%	56%	22%
7	Eye clinic support and signposting (ECLO)	31%	54%	52%
8	Genetic counselling	29%	42%	25%
9	Genetic testing	46%	39%	43%
10	Support to change careers	12%	33%	28%

From this, it's possible to extract the top five services that respondents said they were unable to access, either because they didn't know about them, or because they were not available:

1. Eye clinic support and signposting (ECLO)
2. Workplace occupational support
3. Counselling
4. Genetic testing
5. Advice on claiming benefits

Two services – benefits advice and counselling – appear within both top five lists: among the services making the biggest positive difference for those who access them, and those that are hardest to access.

*“It was only when I specifically asked, several years later, having lost my driving licence, that I was registered. And even then nobody suggested a blue badge or referred me to support agencies. One issue with this is that ... hospital clinics only know about their own local services.”*

## Support from people and groups

As well as these statutory or more formal services, 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
Other national sight loss charities	65%	71%
Informal meetings with others affected	49%	71%
A local sight loss organisation	56%	66%
Retina UK staff or volunteers	57%	58%
Online sight loss community	45%	56%

*“I enjoy some social activities now but with a friend as my guide and support, and enjoy attending clubs like audiobook club and being on committees of groups in my area.”*

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

	I don't need this now	I can't access this
Other national sight loss charities	22%	13%
Informal meetings with others living with sight loss	30%	22%
A local sight loss organisation	25%	18%
Retina UK staff or volunteers	25%	19%
Online sight loss community	28%	27%

We provided space for people to comment on other kinds of support. Some said they would like to have access to supportive peer communities that felt more suitable to their particular situation: for example, people of a similar age to them, or working in the same industry.

*“I would like to talk to other people with RP within my age group - I feel quite isolated as I am unable to talk to people with the same condition.”*

## **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:

	% using
Cane	63%
Flashlight or enhanced illumination	50%
Smartphone with accessibility features	44%
Smart home device (Alexa, Google, etc)	33%
Tablet with accessibility features	33%

We also asked which equipment or aids respondents would like to use, but don't currently. The top items were all tech devices or applications: smart glasses (30% would like to use this); followed by tablet with accessibility features / standalone reading device (both 21%); smart home device (20%); and smartphone with accessibility features (19%).



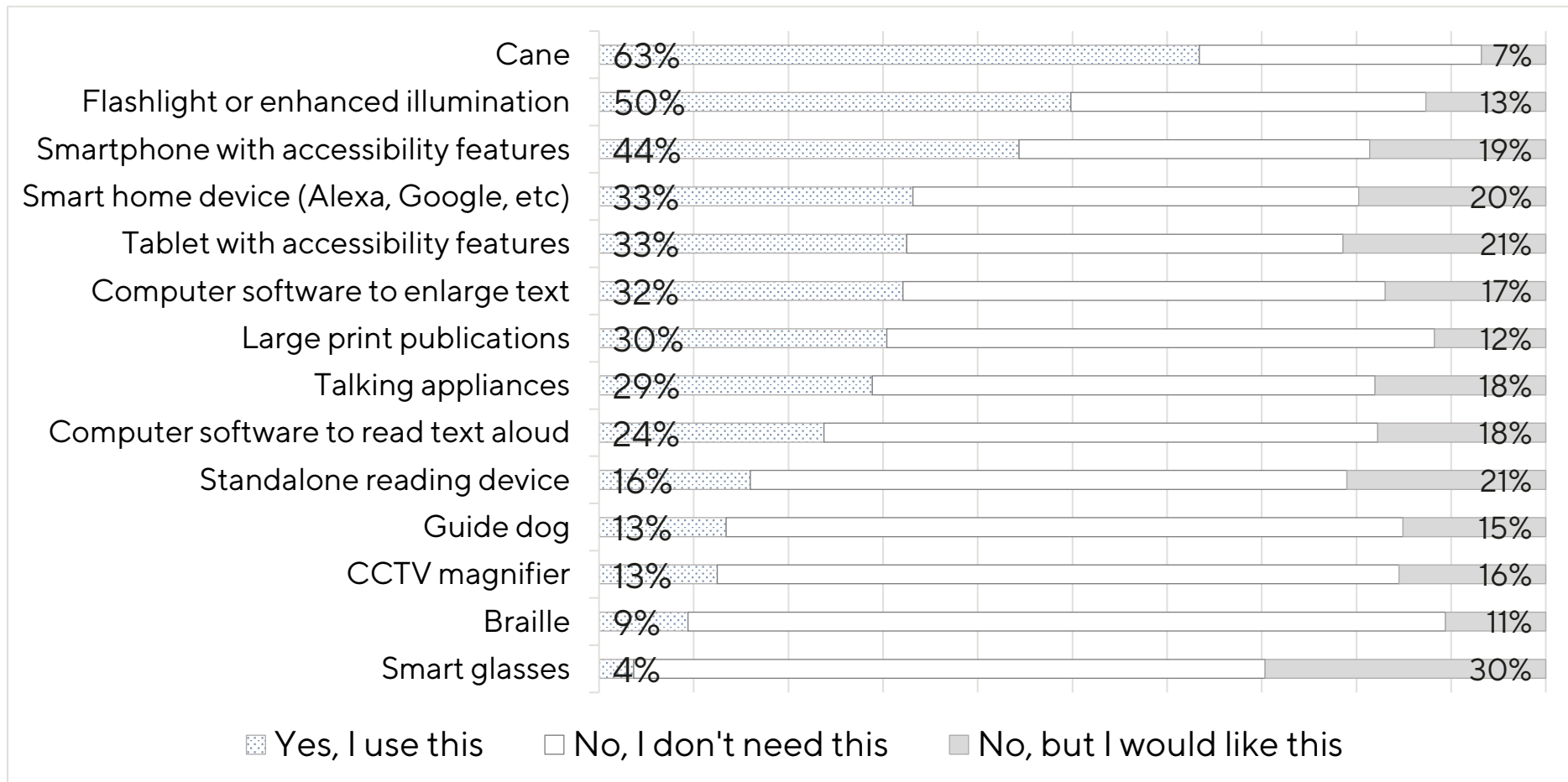


Figure 8: Q18 Which of these types of aids, assistive technology or communications support do you use? (all respondents)

While some of these items can be expensive, a lack of knowledge on how to get hold of them was given equal weight as the main barrier to access. Other barriers included not being aware of these aids, or not feeling confident or skilled to use them:

Don't know how to obtain	42%
Too expensive	41%
Did not know it existed	28%
Not confident to use / lack skills	26%
Told it is not suitable or available	11%

This suggests an information gap when it comes to knowing about the range of aids available, particularly tech devices and applications, and how these can be obtained.

# Clinical research

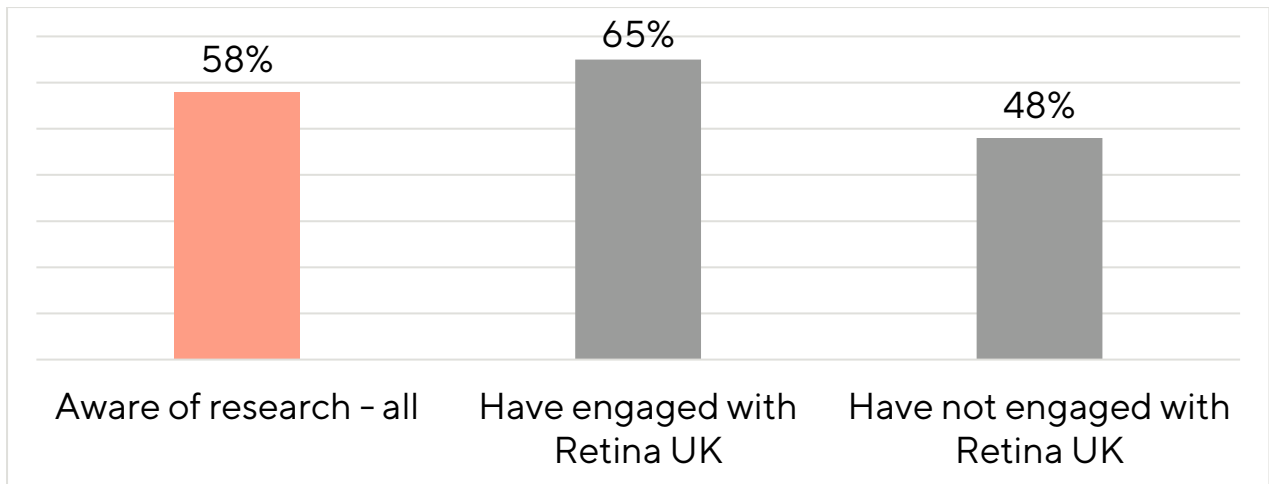
## Key findings

- More than half (58%) 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. Awareness of research is much higher among those who have engaged with Retina UK compared with those who haven't (65% compared with 48%).

*"The main information I want is to know what research is being done to find a cure and whether I qualify for this."*

More than half of respondents (58%) were aware of clinical trials or other ongoing research into their type of sight loss.

Awareness of research was much higher among those who have engaged with Retina UK compared with those who haven't engaged (65% compared with 48%).



*Figure 9: Q21 Are you aware of any clinical trials or other ongoing research for your type of sight loss?*

Retina UK was the top source of research information for respondents, with almost two thirds (64%) of those who knew about research citing Retina UK as a source. We were twice as likely to be mentioned as the next highest source (ophthalmologist).

Retina UK	64%
Ophthalmologist (eye specialist)	32%
Online community	17%
Web search	17%
A charity or patient group (not Retina UK)	8%
In the media	7%
Clinicaltrials.gov website	5%
Word of mouth	3%
UK Clinical Trials Gateway website	3%
Optometrist	2%
GP	1%

Just over half of people (57%) would like to participate in research (a clinical trial or other kind of research) but haven't yet. A further 20% have participated in research, and 22% say they do not want to.

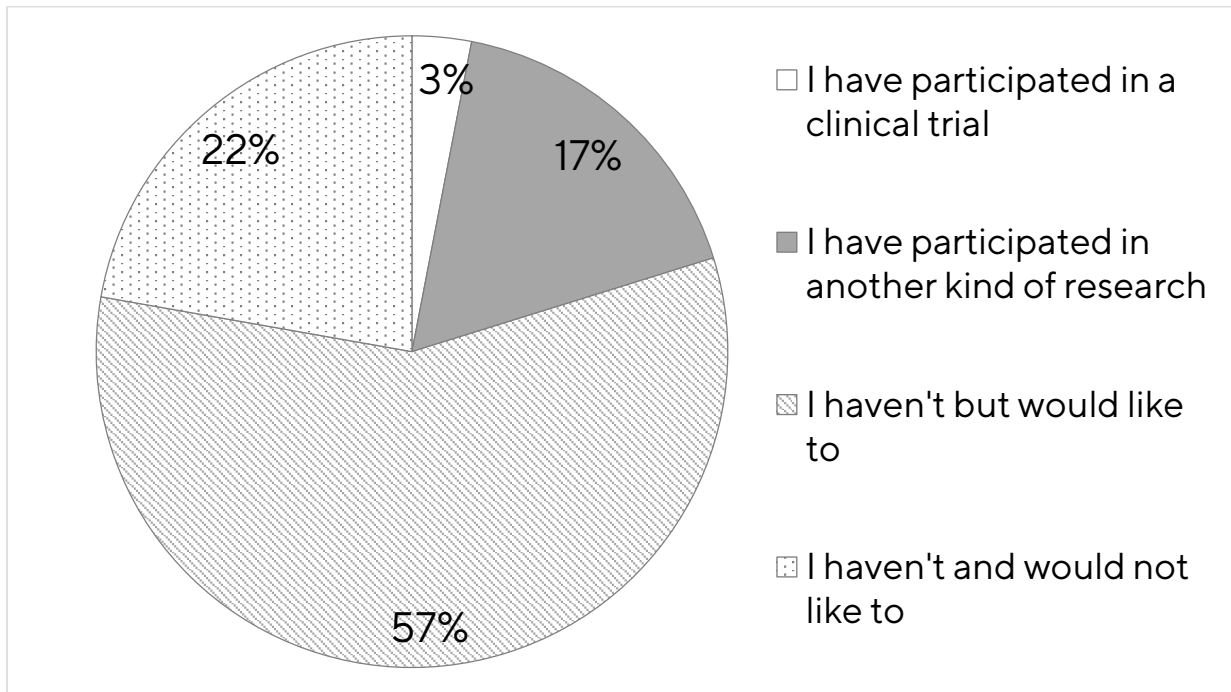


Figure 10: Q23 Which of these best describes your experience of clinical trials or other research into your type of sight loss? (all respondents)

*“At 72 I do not need or expect support or benefit from ongoing research, but do hope it may be available to my daughter and granddaughter who have been diagnosed with RP.”*

# Attitudes towards Retina UK

## Key findings

- Many hear about us for the first time from a health professional (24%).
- Seven in 10 (70%) have engaged with Retina UK in some way.
- 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. They are less likely to agree people with sight loss have a big say in what we do.
- Four in five (81%) agree that, thanks to Retina UK, they are better informed about ongoing research.
- 80% of people rate our services as 'excellent' or 'good'.
- Our newsletters achieve highest satisfaction and usage levels, followed by our website.

## Knowing about Retina UK

Many people hear about Retina UK for the first time from a health professional. This has changed little over the past 20 years, and shows the ongoing importance of the health service workforce in ensuring people are aware of support from Retina UK.

*“When I asked if I would go blind, was told they thought I would. They gave me a sheet of paper with the helpline number of Retina UK. They did help me.”*

There has been a significant shift in the past 20 years from people relying on word of mouth to know about Retina UK, to being able to find us through the internet.

The top ways people first hear about us:

	All	Diagnosed >20yrs ago	Diagnosed <20yrs ago
From a healthcare professional	24%	26%	22%
Word of mouth	21%	26%	13%
Internet search	20%	11%	34%
From another charity or support group	10%	9%	11%
In the media	7%	7%	7%
Not before this survey	6%	7%	5%

## Engaging with Retina UK

Seven in ten (70%) of respondents said they had engaged with Retina UK in some way, through one or more of the following routes:

Member	50%
Access info and/or support	31%
Donate or raise funds	30%
Belong to Local Group	6%
Volunteer	3%
Paid staff member	0%
None of these	30%

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 (71% compared with 65%)
- Respondents diagnosed more than 20 years ago, compared with those diagnosed since then (73% compared with 66%)
- Respondents diagnosed with RP (retinitis pigmentosa), compared with those with other diagnoses (75% compared with 57%)
- As we saw earlier, those who say they are currently managing their sight loss well are more likely to have engaged with Retina UK than those who say they are not managing well (73% compared with 61%)

## Perceptions of Retina UK

Respondents were mostly happy to agree that Retina UK behaves in line with our own values: that we're approachable, trustworthy, and ambitious on behalf of people with sight loss.

The exception is the statement *'People with inherited sight loss have a big say about what Retina UK does'*. Only 42% of respondents agreed with this – a much lower percentage than for the other three statements. However, only 5% of respondents actually *disagreed* with this statement – the remaining 51% were neutral.



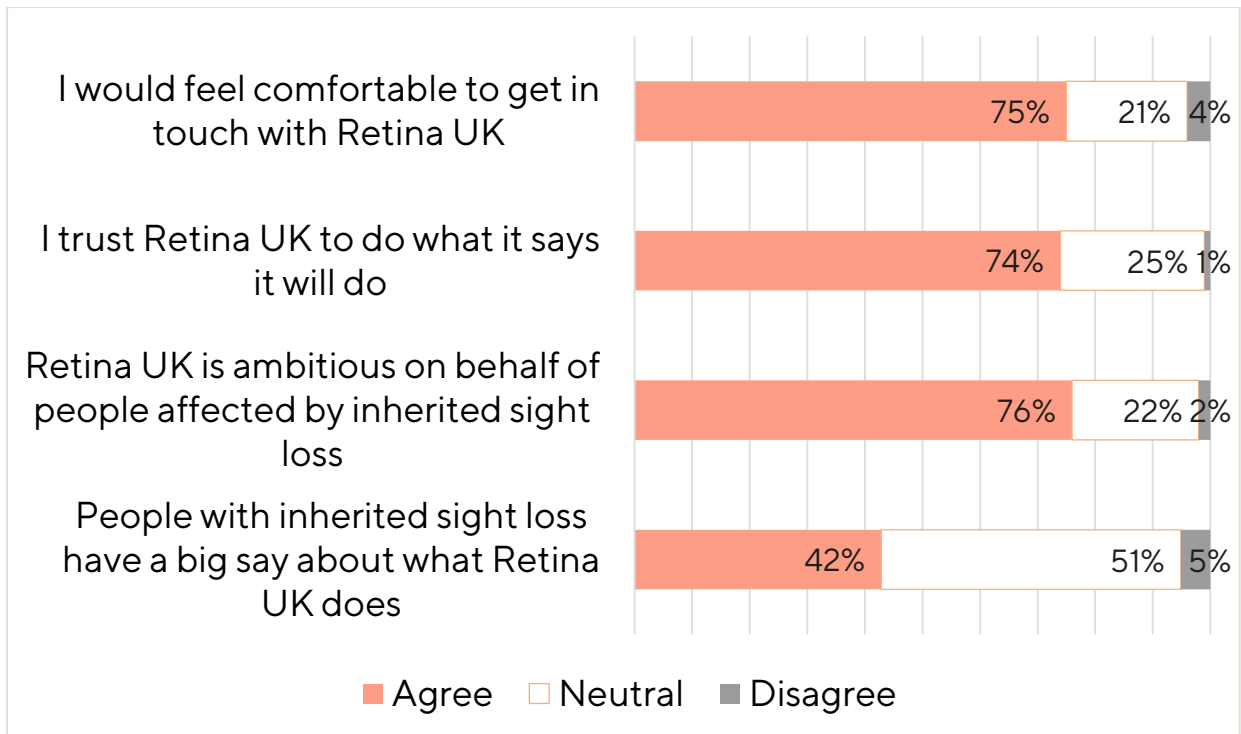


Figure 11: Q26 How far do you agree with each of these statements about Retina UK? (all respondents)

### The difference we make

More than eight in 10 respondents (81%) agreed that, thanks to Retina UK, they are better informed about ongoing research.

Agreement is higher among those who were diagnosed more than 20 years, compared to those diagnosed since then (87% compared with 71%), and among those who are sight loss registered compared with those who are not (82% compared with 77%).

Almost half (45%) agreed that Retina UK helps them have greater awareness of the support available to them. Agreement is higher among those who are sight loss registered compared with those who are not (46% compared with 37%).

One in five (20%) agreed that Retina UK helps them feel more confident in managing the challenges of sight loss. This is higher among those

diagnosed within the past 20 years, compared with those diagnosed longer ago (26% compared with 16%).

Only 7% agreed that, thanks to Retina UK, they are more able to lead a fulfilling life. This is considerably lower than the others, and may be due in part to the language used in the statement. A 'fulfilling life' is perhaps too an abstract a concept for people to feel able to evaluate.

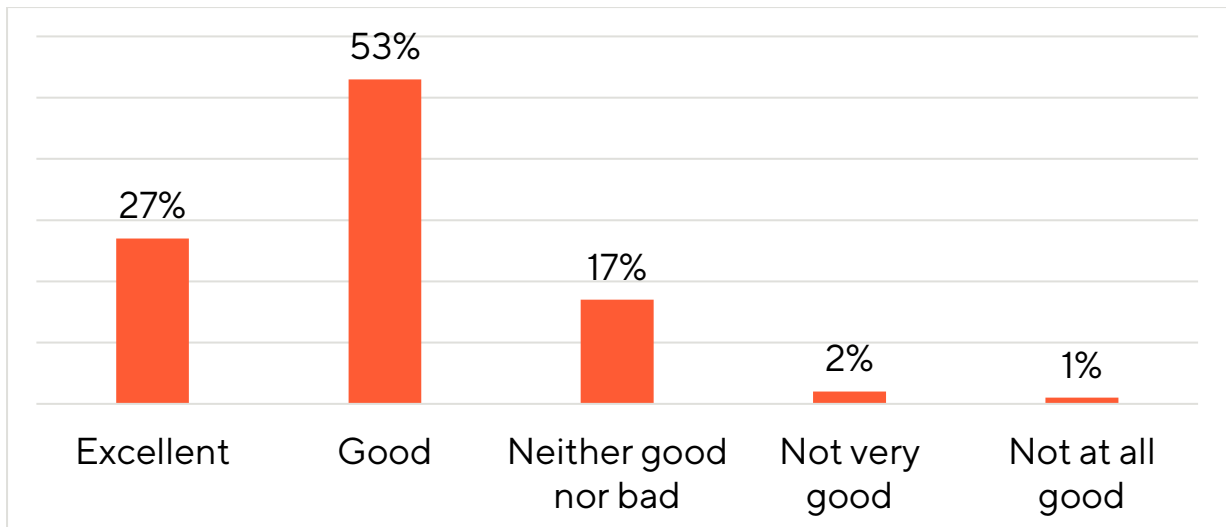


Figure 12: Q29 In your opinion, what difference does Retina UK make to you? (all respondents)

*"Just want to say thank you for all you do!"*

### Retina UK's information, support and services

Respondents who have used our information, support and services were very positive about these, with 80% describing them as 'excellent' (27%) or 'good' (53%). Only 3% said our services were 'not very' or 'not at all' good.



*Figure 13: Q28 Overall, how would you rate the information, support and services available from Retina UK for people affected by inherited sight loss? (users of services only)*

The most accessed information, support and services were our newsletters, website, helpline, information days and local groups.

*“Retina UK gave me the best support after my diagnosis. The support, patience, empathy, kindness and understanding I received from helpline staff is one of the main reasons I came to terms with my diagnosis.”*

Satisfaction levels (from totalling ‘very’ and ‘quite’ satisfied) were highest for our newsletters, website, annual conference, information days and helpline<sup>1</sup>:

<sup>1</sup>Two services (information for employers and teachers) have been excluded from this table, as the response numbers were too small to give reliable findings.

	Accessed	Satisfied
Regular newsletters	75%	94%
Website	52%	93%
Annual conference	16%	89%
Information Days	24%	88%
Helpline	25%	87%
Online support groups	16%	87%
Support with fundraising	17%	86%
Info for children & young people	3%	81%
Local Groups	18%	73%
Telephone befriending service	4%	73%

People diagnosed within the past 20 years access Retina UK services differently from those diagnosed before that, showing a preference overall for online channels over face-to-face.

	Diagnosed <20 years ago (% used)	Diagnosed >20 years ago (% used)
Regular newsletters	67%	80%
Website	67%	42%
Annual conference	11%	20%
Online support groups	21%	13%
Local Groups	13%	22%

## Information topics

Respondents wanted to hear more from Retina UK on treatment updates, research progress and managing life with sight loss:

Updates on treatments	77%
Updates on sight loss research funded by Retina UK	68%
Opportunities to participate in sight loss research	59%
Information on assistive technologies	56%
Managing everyday life with sight loss	52%
Information and support for my local area	47%
Updates on relevant national health and social care policy and practice	41%
Stories about other people living with sight loss	32%
How I can continue to work or study	25%
Ways to fundraise or donate to Retina UK	17%
Opportunities to volunteer	14%

# Appendix: data tables for charts

Figure 2: Q1 Are you severely sight impaired or sight impaired? (all respondents)

Registered as severely sight impaired	65%
Registered as sight impaired	19%
Degree of loss does not meet criteria	9%
Chosen not to be registered	6%
Total registered	84%
Total not registered	16%

Figure 3: Q6 Right now, what impact does your sight condition have on your quality of life overall? (all respondents)

No impact	1%
Mild impact	10%
Moderate impact	36%
Severe impact	38%
Very severe impact	15%
Total experiencing some impact	99%
Total experiencing severe / very severe impact	53%

Figure 5: Q10 Thinking back to your diagnosis... please select the relevant box for each statement (all respondents)

	>20 yrs ago	10- 20 yrs ago	5-10 yrs ago	1-5 yrs ago	<1 year ago
I was given the opportunity to ask questions	53%	68%	82%	80%	85%
The person giving my diagnosis had a good knowledge of my condition	73%	78%	84%	80%	85%
The person giving the diagnosis understood how I might be feeling	43%	54%	59%	43%	61%
I was told about ongoing support available to me	29%	39%	41%	34%	46%
I was told about the support available from Retina UK	19%	23%	21%	22%	16%
I was offered emotional / psychological support	7%	10%	19%	8%	23%
I was offered genetic counselling	11%	22%	35%	49%	53%

Figure 7: Q13 How satisfied are you with the ongoing care you receive from your ophthalmologist? (respondents with an ophthalmologist involved in their ongoing care only)

Very satisfied	37%
Quite satisfied	40%
Not very satisfied	12%
Dissatisfied	3%
No longer have appointments	7%
Net satisfaction	77%



Figure 8: Q18 Which of these types of aids, assistive technology or communications support do you use? (all respondents)

	Yes, I use this	No, I don't need this	No, but I would like this
Cane	63%	30%	7%
Flashlight or enhanced illumination	50%	38%	13%
Smartphone with accessibility features	44%	37%	19%
Smart home device (Alexa, Google, etc)	33%	47%	20%
Tablet with accessibility features	33%	46%	21%
Computer software to enlarge text	32%	51%	17%
Large print publications	30%	58%	12%
Talking appliances	29%	53%	18%
Computer software to read text aloud	24%	59%	18%
Standalone reading device	16%	63%	21%
Guide dog	13%	71%	15%
CCTV magnifier	13%	72%	16%
Braille	9%	80%	11%
Smart glasses	4%	67%	30%

Figure 11: Q26 How far do you agree with each of these statements about Retina UK? (all respondents)

	Agree	Neutral	Disagree
I would feel comfortable to get in touch with Retina UK	75%	21%	4%
I trust Retina UK to do what it says it will do	74%	25%	1%
Retina UK is ambitious on behalf of people affected by inherited sight loss	76%	22%	2%
People with inherited sight loss have a big say about what Retina UK does	42%	51%	5%