

**THE UK SIGHT LOSS CRISIS
AND CASE FOR INVESTMENT
IN RESEARCH**

**TIME
TO
FOCUS**



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**The need is there.
The science is there.
The talent is there.
The funding is not.**

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ACKNOWLEDGEMENTS

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Chair: **Professor Jonathan Grant**, Professor of Public Policy, Kings College London, and Trustee, Fight for Sight

Members:

Roger Backhouse, Trustee, Retina UK
Matt Broom, Chief Executive, Vision UK
Sarah Campion, Director of Engagement, Fight for Sight
Sherine Krause, Chief Executive, Fight for Sight
Dr Wen Hwa Lee, Chief Executive and Chief Scientist, Action Against AMD
Professor David Spalton, Professor of Ophthalmology and Trustee, Fight for Sight

Mike Thompson, Policy and Public Affairs Manager, Fight for Sight
Toby Watt, Senior Economist, The Health Foundation

Suppliers commissioned by Fight for Sight:

Debbie Kear, Consultant, Kaleidoscope Research
Rachel King, Consultant, Kaleidoscope Research
David McDaid, Associate Professor, LSE
A-La Park, Assistant Professor, LSE
Simon Thomson, Senior Scientific Analyst, Clarivate



FOREWORD

SHERINE KRAUSE

CHIEF EXECUTIVE, FIGHT FOR SIGHT

Sight loss is a major public health issue of our time, affecting more than 2.5 million people. But it is not getting anywhere near the attention and investment needed.

This landmark report puts sight loss in the UK into focus, compiling new insight that reveals the scale of the issue and the economic and human cost of inaction.

Behind the statistics are real people. Which is why this report is informed by interviews with hundreds of people living with the effects of eye conditions day in, day out. It shows just how far-reaching these effects are – from increased outgoings and barriers to work, to loneliness and poor mental health.

I was shocked to discover that people with severe sight loss reported one of the lowest quality-of-life scores compared with many other serious conditions. And that every year, sight loss costs the UK economy more than £25 billion – the majority of which lies outside health and social care.

Importantly, our report also shows that science has the answers.

Fight for Sight is the only UK charity 100 percent focused on eye research. While caring for and supporting people with sight loss is of course vital, now is the time to balance the scales towards investment in research.

I'm proud Fight for Sight funded research has already made possible breakthroughs in choroideremia, glaucoma and Leber congenital amaurosis, improving treatments and even enabling people to see clearly for the first time in decades.

However, there's so much more to do. We won't stop until we've found new treatments and cures for age-related macular degeneration and other leading causes of blindness.

We can't end sight loss alone. This report marks the beginning of the next stage of our journey, working with the government, industry, our partners and supporters to ensure sight loss research gets the attention and investment it needs. Only then can we create a world everyone can see.

My deepest thanks to all those who made this report possible, in particular to our generous funders, The Clothworkers' Foundation, Novartis, Roche and Santen; to our report contributors at the London School of Economics and Political Science, Clarivate and Kaleidoscope; and to the report steering group, who volunteered their time and expertise to steer this project to success. And of course a special thank you to the hundreds of people with sight loss and blindness who generously shared their experiences. These pages tell your story. Finally, thank you for reading and being part of the fight for sight.

Foreword
Professor Sir Peng Khaw



FOREWORD
PROFESSOR SIR PENG KHAW
CONSULTANT OPHTHALMIC SURGEON,
MOORFIELDS EYE HOSPITAL AND
UCL INSTITUTE OF OPHTHALMOLOGY

Eye research changes lives. Over the last decades we have seen the sight and lives of millions of people improved by advances due to research. In many cases, there are now diagnostic tests and treatments where there was nothing before. None of these would have been possible without research.

There has never been a more exciting time for eye research. We know more than ever about the eye and the visual system, and the hundreds of conditions that affect our sight. New technologies such as non-invasive imaging, artificial intelligence, stem cell treatment, laser surgeries and micro devices and implants are making treating and, in some cases, curing sight loss more efficient, accessible and successful.

Breakthroughs in genetics and gene therapy are enabling patients to be diagnosed and treated for a range of conditions that were previously untreatable.

And pioneering studies are paving the way for new treatments for glaucoma and age-related macular degeneration.

But none of this progress will be possible in the future without investment – investment that is presently severely lacking compared with other diseases.

This report is very important because it shows the enormous potential of research, not just to further science but to transform many more lives in the future.

With the increase in ageing populations around the world, a huge number of us will experience an eye problem if we live an average life span. This increase in the number of people with vision-related problems presents a significant and increasing challenge to our health and social care systems. Many people still see sight loss as inevitable – a part of growing older that we must simply accept. But this is not the case at all. Hundreds of sight loss conditions can be treated, and even prevented, if diagnosed early. For those that are still currently untreatable, research offers hope for most of these conditions in the future. This includes innovations that may make treatments more easily available in most parts of the world, including in the developing world.

Education is urgently needed to make the public and policy makers aware that the UK sight loss crisis is a problem that can and must be solved.

The challenge ahead is huge, made even larger by our ageing population and, most recently, the Covid-19 pandemic, which has increased the need for better, more innovative and rapid solutions to vision challenges. It is a challenge we can and must face.

Eye researchers across the UK and globally are close to finding new and better treatments and cures for the many causes of sight loss and blindness. As this report says, 'The need is there. The science is there. The talent is there. The funding is not.'

Time to Focus provides us with a clear picture of sight loss in the UK and its economic, social and personal impacts. It should be a great incentive to invest in eye research with the very significant returns it will bring to people in the UK and around the world.

This new insight provides the motivation and tools needed to double efforts and end this preventable crisis. There really is no time to lose.



EXECUTIVE SUMMARY



Right now, 2.5 million people in the UK are living with sight loss.¹

This huge number of people have hundreds of eye conditions and other illnesses that lead to impaired vision, from age-related macular degeneration to corneal dystrophies. And all these conditions have one thing in common – they have a profound impact on the people living with them. It's no wonder sight is the sense people most fear losing.²

¹ According to Global Burden of Disease data, 2.5 million people in the UK have an eye condition that affects their sight, more than 1.5 million have moderate or severe sight loss, and 400,000 people are blind. This compares with prevalence estimates of 850,000 for dementia and 2.9 million for cancer. www.alzheimers.org.uk www.macmillan.org.uk

² From a YouGov poll of more than 2,000 GB adults conducted on behalf of Fight for Sight in September 2019. Eighty four percent of respondents said they feared losing the ability to see more than other senses.

Our ageing population is making the most prevalent eye conditions more and more common. **In fact by 2050 the number of people in the UK living with sight loss will jump to 3.5 million.³**

This is a public health crisis that can no longer be ignored.

On top of the impact of sight loss on all areas of people's lives, made even more challenging by the coronavirus pandemic, treating and caring for people with eye conditions is placing enormous strain on the National Health Service (NHS) and wider UK economy.

The UK is not alone. Sight loss is a global crisis that demands a global response. Around the world, at least 2.2 billion people have sight loss or blindness. And at least 1 billion have a condition that could have been prevented or has yet to be treated. It's estimated that more than a million people in the UK are living with avoidable sight loss.⁴

Research is vital to relieve this pressure by finding cures and new treatments that transform lives.

As the UK's leading charity dedicated to funding pioneering research, we have made transformational treatments possible. **But sight loss research is getting a fraction of the investment it desperately needs – and this situation is being exacerbated with the advent of Covid-19.**

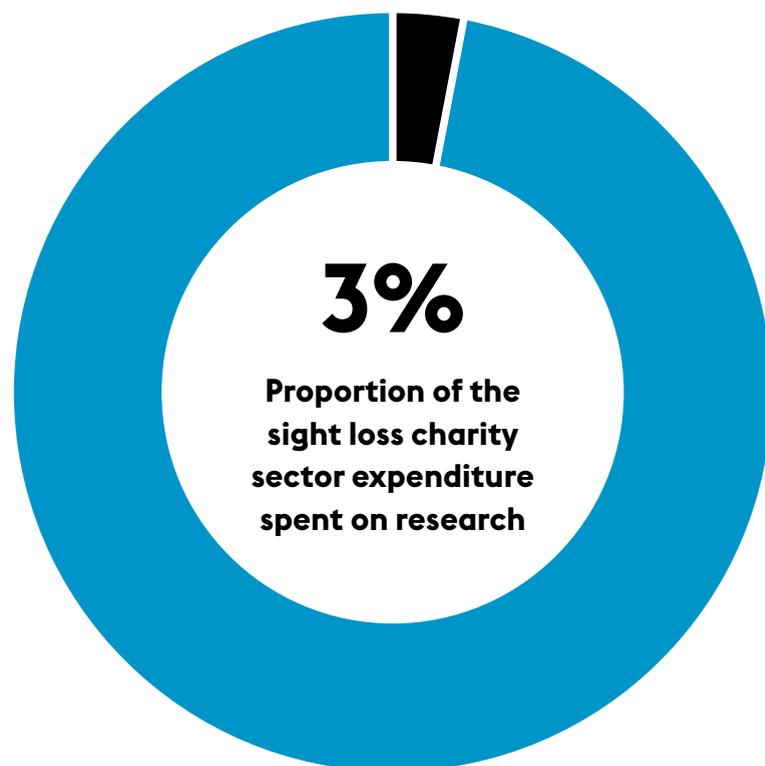
In 2018, just over 1.5 percent (£24 million) of the £1.4 billion that UK Research and Innovation, government and other public bodies invested in medical research was for eye research.

That's a total of just £9.60 for each person affected by sight loss in the UK.⁵

³ Figure derived from our LSE model based on Global Burden of Disease data.

⁴ Based on IAPB Vision Atlas figures. atlas.iapb.org/

⁵ Calculated from UK Health Research Analysis 2018 (UK Clinical Research Collaboration, 2020) hrcsonline.net/reports/analysis-reports/uk-health-research-analysis-2018/



And in addition to this figure, across the sight loss charity sector in 2018-19, just three percent of charity expenditure (£12.5 million) was spent on research, with a vast majority going towards care and support.⁶

A lack of awareness of the causes and treatments of sight loss is robbing people of their vision and quality of life. This is an injustice that demands to be corrected.

We must urgently come together – government, health services, businesses, charities and researchers – to create a world everyone can see.

⁶ A Fight for Sight figure calculated from the proportion of income invested in eye research in 2018 from the top 16 sight loss charities: Blind Veterans, Catholic Blind Institute, Deafblind UK, Fight for Sight, Guide Dogs for the Blind, Macular Society, Moorfields Eye Charity, National Eye Research Charity, RNIB, Royal Blind School, Scottish War Blinded, Seeability, Sense, The Royal Society for Blind Children, Thomas Pocklington Trust, WESC Foundation.

A CLEARER PICTURE OF SIGHT LOSS

OUR RESEARCH FINDINGS

As a leader in the fight against sight loss, we brought together sector partners, academics and people with eye conditions to get a more complete picture of sight loss in the UK and catalyse action. This definitive report focuses on the most urgent findings.

The report is accompanied by a new costing tool that, for the first time, empowers decision makers to dynamically model current and future sight loss prevalence and the cost of treatment and services (see page 64).

Together, these insights and the costing tool give us a clearer picture than ever before of the impact of sight loss and the scale of the challenge to be met.

An extensive review of the literature on the economic impact of eye conditions – considering a wide range of costs for a more accurate calculation – has revealed that eye conditions cost the UK economy a staggering **£25.2 billion** a year. That's more than the combined annual expenditure of both the Home Office and the Ministry of Justice. And we estimate this cost will rise to **£29.9 billion** a year by 2030 and **£33.5 billion** a year by 2050.

We can reveal that **84 percent** of the economic costs of sight loss lie outside the health and social care system, reflecting the costs of informal care by family and friends, productivity losses and quality of life impacts, highlighting the far-reaching impacts on the UK economy.



2050

£33.5 BILLION



2030

£29.9 BILLION

COST OF VISUAL
IMPAIRMENT TO THE
UK ECONOMY



2017

£25.2 BILLION

With the **health and social care** sector struggling to meet the demands of sight loss, the reliance on family and friends to fill the gaps is costing the UK economy **£8.5 billion** a year – a third of the total cost.

Despite disability legislation a high number of working-age people are **excluded from the workplace** because of their eye condition, costing the UK economy up to **£7.4 billion** – nearly another third of the total costs.

And the impact of sight loss on people's **quality of life**,⁷ with knock-on effects on their productivity, accounts for up to **£4.6 billion** – almost a fifth of the total costs.

However the health and social care costs alone are massive. Today, **treating sight loss** is costing the NHS and social care services up to **£3.9 billion** a year. Other costs contributing to the total of £25.2 billion include education costs, welfare costs and device costs.

Our new costing model shows that if we **reduce the prevalence** of eye conditions by just one percent each year we could make a cumulative saving to the UK economy of up to **£3 billion** over the next decade and **£9.5 billion** by 2050. This would save NHS and social care services a potential **£1.5 billion** by 2050.

For the first time our model reveals that the lifetime non-health care costs of sight loss for someone blind from birth are conservatively estimated as **£621,384**.

And a new case of **age-related macular degeneration** in an adult aged 50 or over, causing at least moderate visual impairment, costs the UK economy **£73,350** over the person's lifetime, while the lifetime cost of **glaucoma** to the economy is **£49,800** per person. Reducing the prevalence of these conditions by just 14 or 20 cases respectively could save the UK economy **£1 million** in lifetime costs.

⁷ Approximated by placing a monetary value on the disability adjusted life years associated with visual impairment and excluding productivity costs to avoid potential double counting.

These figures are rising with our ageing population and, in the shorter term, due to delays to treatment caused by the coronavirus pandemic.

Using our glaucoma incidence model, we estimate that for every 100 people aged 50 to 54 with probable glaucoma who are identified and treated up to a year late, five more people will progress earlier than anticipated to moderate visual impairment, adding up to an additional cost to society of **£28,098** a year.⁸ Applied to the thousands of cases of glaucoma requiring treatment, this represents an enormous additional cost to the health service.

Our insight from surveys of almost 800 people living with eye conditions, including family members and carers, makes clearer than ever how sight loss affects all areas of life. And the more severe the sight loss, the greater the negative impact. Interestingly, almost a third of the people we surveyed have more than one eye condition and over two thirds are living with another health condition.

We found that sight loss has a significant **financial impact** on people living with eye conditions. As expected, the biggest financial impact is on people of working age, with over a third saying they are struggling financially as a household because of continuing barriers to employment, decreased income and increased outgoings.

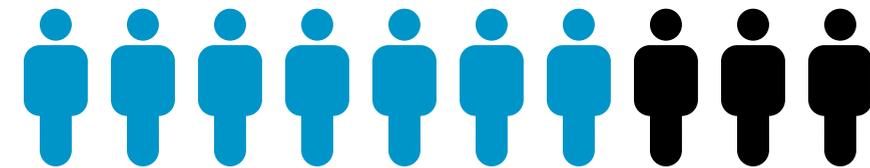
The biggest impact of eye conditions on the people we surveyed is on their **emotional wellbeing**, with almost all feeling living with their eye conditions makes life harder. Significantly, the quality of life of people with severe sight loss⁹ is lower than of people with a range of other severe physical and mental health conditions, including depression, arthritis and advanced breast cancer. This should be a major cause for concern.

⁸ Based on past studies that have suggested there is a five percent difference in the rate of progression from mild to moderate visual impairment per year if an individual is treated compared with an individual who is not treated.

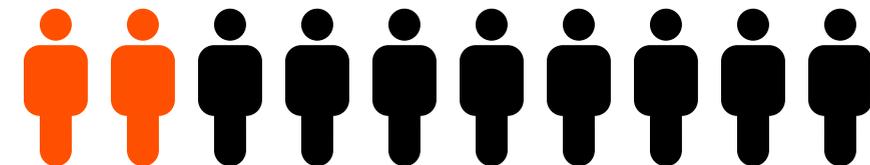
⁹ A score of 0.582, where a value of 1 indicates a year lived in full quality of life and 0 indicates a year with no quality of life.

Seven in 10 people feel some area of their life is limited by their eye condition and many think it has had a negative impact on their **personal relationships**. The mental health impact of sight loss is highest on those with a low annual household income, adding to anxiety and depression. And our follow up survey shows the coronavirus pandemic affecting the emotional and social aspect of people's lives still further.

In relation to **health**, our insight uncovers that one in five people is not getting the support they need to go about their daily lives. Almost all respondents have some type of check-up, medication or treatment for their eye conditions; however, many find these uncomfortable or painful. Again, the coronavirus pandemic has made it even harder for people with sight loss to access the treatment and care they need, with one in four concerned their eyesight deteriorated during lockdown.



7 in 10 feel that their life is limited by their eye condition



1 in 5 is not getting the support they need to go about their daily lives

THE POSSIBILITIES OF SCIENCE

SOLUTIONS

Many people don't realise the life-changing impact sight loss research can have. But we know it has the power to transform lives.

Our extensive analysis of eye research publications shows the scope of the influence and impact UK research has on fighting sight loss globally. It reveals a UK research sector collaborating with sight loss researchers and funding partners across the globe, producing publications with more impact than the world average.

Our analysis also shows Fight for Sight's expertise in identifying and carrying out research with a greater impact than that of other, often bigger, funders and among the best in the world. Our publications receive 80 percent more citations and are twice as likely to be highly cited than the world average.

Fight for Sight is the only national charity 100 percent focused on funding ground-breaking research into eye conditions that cause sight loss. We're investing nearly seven million pounds in 117 projects at leading universities and hospitals across the country, supporting the brightest minds in vision research. Our findings show the research we fund is getting results, with hundreds of researchers so close to life-changing breakthroughs if we could only fund more research.

However, the challenge of transforming the lives of 2.5 million people with hundreds of different conditions in the UK alone is enormous. And it will only get bigger with our ageing population and in the face of Covid-19, which our research shows has had a devastating impact on the research landscape.

The need is there. The science is there.

The talent is there.

The funding is not.

Our new costing model shows the enormous economic impact of reducing the prevalence of eye conditions in the UK, through increased investment in eye research and other prevention measures.

- From our model we estimate that by reducing the prevalence of eye conditions by just one percent each year we could make a cumulative saving to the UK economy of up to £3 billion over the next decade and £9.5 billion by 2050. This would save NHS and social care services a potential £1.5 billion.
- Reducing age-related macular degeneration prevalence by one percent each year could save the UK economy nearly £1.2 billion by 2050
- Reducing glaucoma prevalence by one percent each year could save the UK economy over £325 million by 2050
- Reducing type 2 diabetes-related diabetic retinopathy prevalence by one percent each year could save the UK economy over £150 million by 2050

Age-related macular degeneration reduced by 1% each year

£1.2bn

**ECONOMIC IMPACT OF
REDUCING THE PREVALENCE
OF EYE CONDITIONS
IN THE UK BY 2050**

Glaucoma reduced by 1% each year

£325m

Type 2 diabetes-related diabetic retinopathy reduced by 1% each year

£150m

To achieve the scientific breakthroughs that make diagnosing, treating and reversing sight loss possible, a significant increase in eye research funding is needed, now. This is more important than ever in the context of Covid-19.

Investing in research to tackle these leading causes of sight loss has the potential to deliver a significant return on investment for the UK economy, relieve the strain on the NHS and social care services and, most importantly, transform hundreds of thousands of lives.

Working together, we can radically reshape the future for everyone affected by sight loss.

It's time to focus.



RECOMMENDATIONS

This report shows the vital importance of funding pioneering eye research to tackle the UK sight loss crisis. We all have a role to play.

Here are our top five recommendations based on our findings. You'll find more detailed recommendations throughout the report.

Government and funding bodies

Double public investment in sight loss research from £24 million (1.5 percent of public grant funding for medical research) to at least £50 million by 2030 – and use our flexible costing model to plan for the future.

While doubling investment in eye research would still only take us part of the way, increased investment would transform hundreds of thousands of lives, save the economy money, and keep the UK at the forefront of ophthalmology research.

Increased investment of this scale is possible when the government takes a health condition seriously. Between 2012 and 2015 the UK government doubled investment into dementia medical research and in 2017/18 they invested the equivalent of £97 for every person with dementia.¹⁰ In contrast just £9.60 is currently invested in eye research for each person with sight loss.

¹⁰ www.dementiastatistics.org

Our study shows that a focus on investment in new treatments for high-cost and high-prevalence conditions like age-related macular degeneration and diabetic retinopathy – which are currently untreatable in many cases – could have the biggest impact.

Sight loss charities

Invest more income in eye research – 3 percent is not enough.

This would begin to tip the scales toward investment in early detection, prevention and cure, alongside care and support, helping to transform more lives and save money in the long term. Scaling-up collaboration with other charities and people with sight loss would maximise the efficiency and impact of investment in eye research.

Recommendations

The sight loss research sector, including funders and pharmaceutical industry

Commit investment, collaborate more - and scale up.

This would enable the discovery of new ways to diagnose more eye conditions early and target new treatments that stop the progression of eye conditions and restore people's sight. Research charities, industry and other funders should support more epidemiological research that will generate accurate population-level data to identify areas of greatest need. Industry partners can then play a leading role to scale up translation towards transformative treatments.

Health service commissioners and providers

Focus on prevention of sight loss and take a holistic approach.

This would reduce much of the need for care and support for people with sight loss, helping reduce costs, and ensuring more people with eye conditions live healthy, happy, independent lives.

Our supporters

Continue to be part of the vital mission to end sight loss.

Enable us to spread the word and campaign on this issue – and you can donate to help us fund more research. You can be part of something huge by helping us tip the balance to ensure sight loss research gets the attention it deserves.

OUR RECOMMENDATIONS:

GOVERNMENT AND FUNDING BODIES

DOUBLE INVESTMENT IN SIGHT LOSS RESEARCH

EYE CHARITIES

INVEST MORE IN EYE RESEARCH

SIGHT LOSS RESEARCH SECTOR

COMMIT INVESTMENT & COLLABORATE MORE

HEALTH SERVICE COMMISSIONERS AND PROVIDERS

FOCUS ON PREVENTION & TAKE A HOLISTIC APPROACH

OUR SUPPORTERS

BE PART OF THE MISSION TO END SIGHT LOSS

INTRODUCTION

Right now, 2.5 million people in the UK are living with sight loss.¹¹

This huge number is made up of people with hundreds of eye conditions and other illnesses that lead to sight loss, from age-related macular degeneration to corneal dystrophies. Some are incredibly painful. Others make ordinary tasks a daily challenge. And almost half are avoidable.

But all these eye conditions have one thing in common – they have a profound impact on the people living with them.

¹¹ According to Global Burden of Disease data, 2.5 million people in the UK have an eye condition that affects their sight, more than 1.5 million have moderate or severe sight loss, and 400,000 people are blind. This compares with prevalence estimates of 850,000 for dementia, and 2.9 million for cancer. www.alzheimers.org.uk; www.macmillan.org.uk

Sight loss affects people’s health, their mental and physical wellbeing, their family and social life, their independence and freedom, their education and job opportunities and their financial security. And the coronavirus pandemic has made these wide-ranging impacts even harder to cope with.

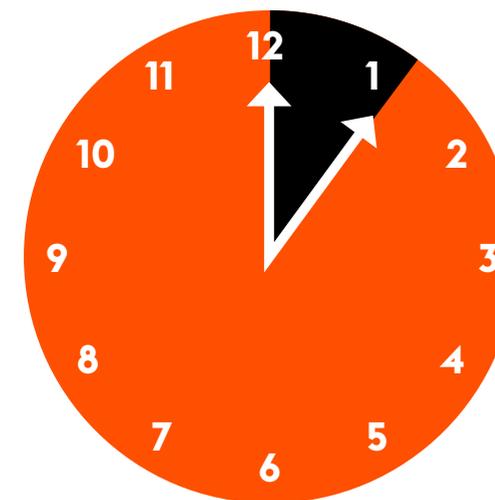
The effects of eye conditions don’t end with the people living with them. Sight loss has a wider impact on friends, family and the whole of society. It has consequences for both publicly and privately funded services. Health, social care, education and employment services are put under increased pressure. And economic productivity is held back as people are shut out of the workforce because of their sight loss or caring responsibilities.

“...the impact of living with sight loss can be very severe and, therefore, as a society, there is the potential loss of full and enriched lives and ... of the ability to work and look after yourself.” **Sight loss professional**

It’s no wonder that people fear losing the ability to see more than any other sense.¹² Every six minutes, someone in the UK is told they’re losing their sight.¹³

¹² From a YouGov poll of more than 2,000 people conducted for Fight for Sight in September 2019. Eighty four percent of respondents said they feared losing the ability to see more than other senses.

¹³ Deloitte Access Economics (2017) Incidence and risk of sight loss and blindness in the UK, RNIB. Available at: www.rnib.org.uk/professionals/knowledge-and-research-hub/incidence-and-risk-sight-loss-and-blindness-uk



EVERY SIX MINUTES

Someone in the UK is told they're losing their sight

COMMON EYE CONDITIONS

AGE-RELATED MACULAR DEGENERATION

Age-related macular degeneration causes loss of central vision as a result of damage to the macula – the tiny central collection of light-sensitive cells found within the retina at the back of the eye. People with the condition may start to experience reduced sharpness of vision, difficulty reading or watching television, distortion, or changes in colour perception.

If detected early enough treatment can help prevent 'wet' macular degeneration from getting worse, but there's currently no treatment for 'dry' macular degeneration, which accounts for 90 percent of cases. For both types once damage has happened, it is, at present, irreversible.

Age-related macular degeneration is the most common cause of permanent and severe sight loss in the UK, with approximately 1.2 million people having the condition in its early stages. Seven hundred thousand people in the UK have late stage age-related macular degeneration.¹⁴

CATARACTS

Just behind the iris (the coloured part of the eye) is the lens, which focuses light onto the retina (the light-sensitive layer at the back of the eye). The lens needs to be transparent to let the light pass through. Cataract is the name for a lens that has become cloudy.

Cataracts results in blurred or hazy vision, and bright lights can cause glare or dazzle. They gradually get worse over time and can cause blindness if left untreated.

Cataract is a major cause of preventable sight loss that it is estimated affects approximately 500,000 people in the UK. Cataract surgery is the most common operation in the Western world; in the UK alone, approximately 400,000 procedures are carried out each year.¹⁵

DIABETIC RETINOPATHY

Diabetic retinopathy is a form of sight loss that can affect anyone with type 1 or type 2 diabetes. It damages the blood vessels supplying the retina – the light-sensitive layer at the back of the eye – which become leaky and bleed.

Managing diabetes properly slows the onset of diabetic retinopathy. If it is detected early enough treatments such as drug injections into the eye and laser surgery can help. But in the early stages blood vessel damage doesn't always cause noticeable symptoms and the condition may go undetected, leading to irreversible complications and, potentially, permanent sight loss.

One hundred and forty four thousand people have diabetic retinopathy in the UK,¹⁶ making it one of the most common causes of sight loss among working-age people. With rates of diabetes on the rise, this figure is expected to increase significantly.

GLAUCOMA

Glaucoma is the name for a group of eye conditions that cause sight loss because of damage to the optic nerve, which connects the eye to the brain. Symptoms include loss of the field of vision, and reduced vision.

Severely raised intraocular pressure causes a marked loss of sight, halos around bright lights, and severe eye pain that comes on suddenly. This can be accompanied by redness and tenderness of the eye, headaches, nausea and vomiting.

Glaucoma damage can be prevented if detected and treated early. However, in most patients it tends to develop slowly and doesn't cause noticeable symptoms until severe damage has already occurred. Sight loss from damage to the optic nerve is currently irreversible.

Around 500,000 people are living with glaucoma in the UK.¹⁷ And it's the second leading cause of blindness in the world.¹⁸

INHERITED EYE CONDITIONS

There are hundreds of genetic disorders that cause damage to parts of the eye, such as the retina, lens and cornea. Although rare, these conditions can cause severe sight loss. Most can't be treated, and where treatments are available, they can have side effects.

Inherited eye conditions are most likely to affect children, continuing into adulthood. And young people with inherited eye diseases may also be more likely to develop additional eye conditions later or develop problems like cataracts at an early age.

More than 100,000 people in the UK, many of them children, have an inherited eye condition affecting the retina or cornea.¹⁹ However this is one of the most exciting and rapidly developing areas of ophthalmology as the responsible genes are being identified and techniques developed to replace or repair them.²⁰

MYOPIA

Myopia, or short sightedness, is a common eye condition where close objects can be seen clearly but those in the distance appear blurry.

Short sightedness can range from mild, where treatment may not be required, to severe, where a person's vision is significantly affected. Treatments include corrective lenses (such as glasses or contact lenses), laser eye surgery to alter the shape of the eye, and artificial lens implants.

It's estimated that up to one in three people in the UK has myopia,²¹ and the condition is becoming more common.

¹⁴ Li JQ, et al. (2019) 'Prevalence and incidence of age-related macular degeneration in Europe: A systematic review and meta-analysis', British Journal of Ophthalmology, published online first: 11 November 2019. Available at: bjophthalmol-2019-314422

¹⁵ Donachie PHJ, and Sparrow JM (2017) Year 2 annual report – The first prospective report of the National Ophthalmology Database Audit.

The Royal College of Ophthalmologists. Available at: www.nodaudit.org.uk/u/docs/20/ughyyctynz/NOD%20Audit%20Annual%20Report%202017.pdf

¹⁶ Mathur R, et al. (London School of Hygiene and Tropical Medicine) (2017) Diabetic eye disease: A UK incidence and prevalence study, RNIB. Available at: www.rnib.org.uk/who-we-are-knowledge-and-research-hub-research-reports-prevention-sight-loss/dr-prevalence

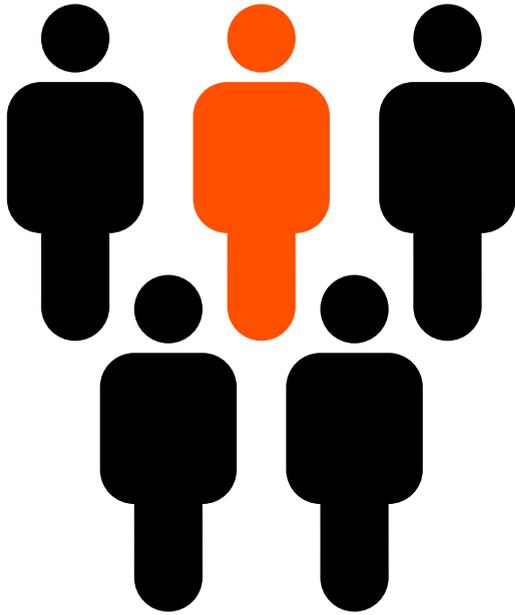
¹⁷ A Fight for Sight estimate based on a review of the available data. Unfortunately data is scarce and more epidemiological studies are needed.

¹⁸ World Health Organization (2004) Glaucoma is second leading cause of blindness globally. Online. Available at: www.who.int/bulletin/volumes/82/11/feature1104/en

¹⁹ A Fight for Sight estimate based on a review of the available data. Unfortunately data is scarce and more epidemiological studies are needed.

²⁰ Fight for Sight has made a major contribution to research in the area. See page 110 for more information.

²¹ NHS (2018) Overview: Short sightedness (myopia). Online. Available at: www.nhs.uk/conditions/short-sightedness



1 in 5

of us will experience significant sight loss at some point in our lives

By 2050 the number of people in the UK living with sight loss will jump to 3.5 million.²²

This is due to the fact the three most prevalent eye conditions are age-related: cataracts, glaucoma and macular degeneration. Our ageing population is making these conditions more and more common.

In addition diabetic retinopathy, an eye condition associated with diabetes, is on the increase. But sight loss is not just a condition of age; thousands of children and young adults are also living with inherited or other eye conditions.

Sight loss could affect any one of us.

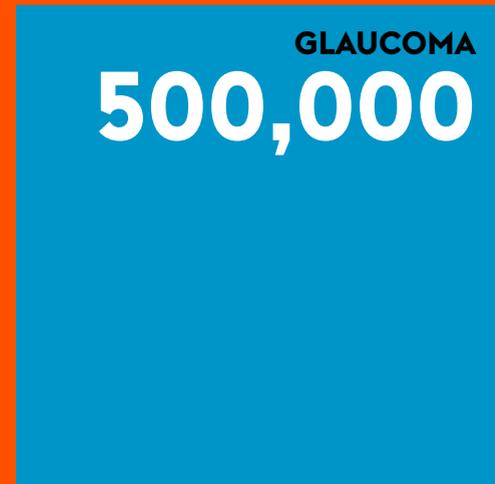
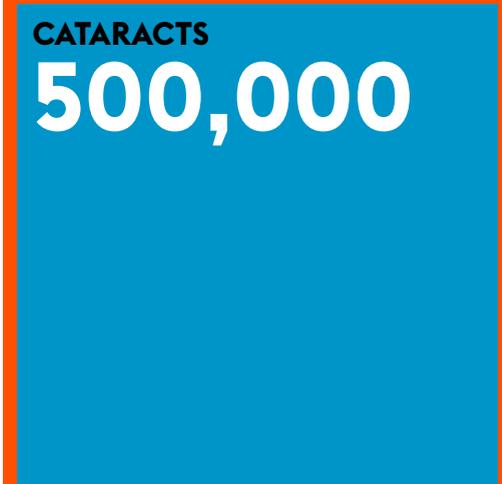
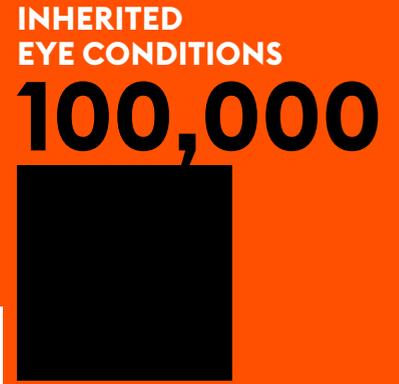
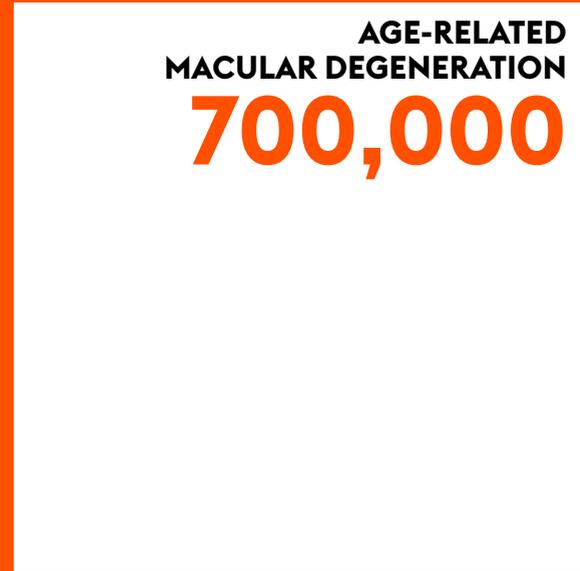
One in five of us will experience significant sight loss at some point in our lives.²³

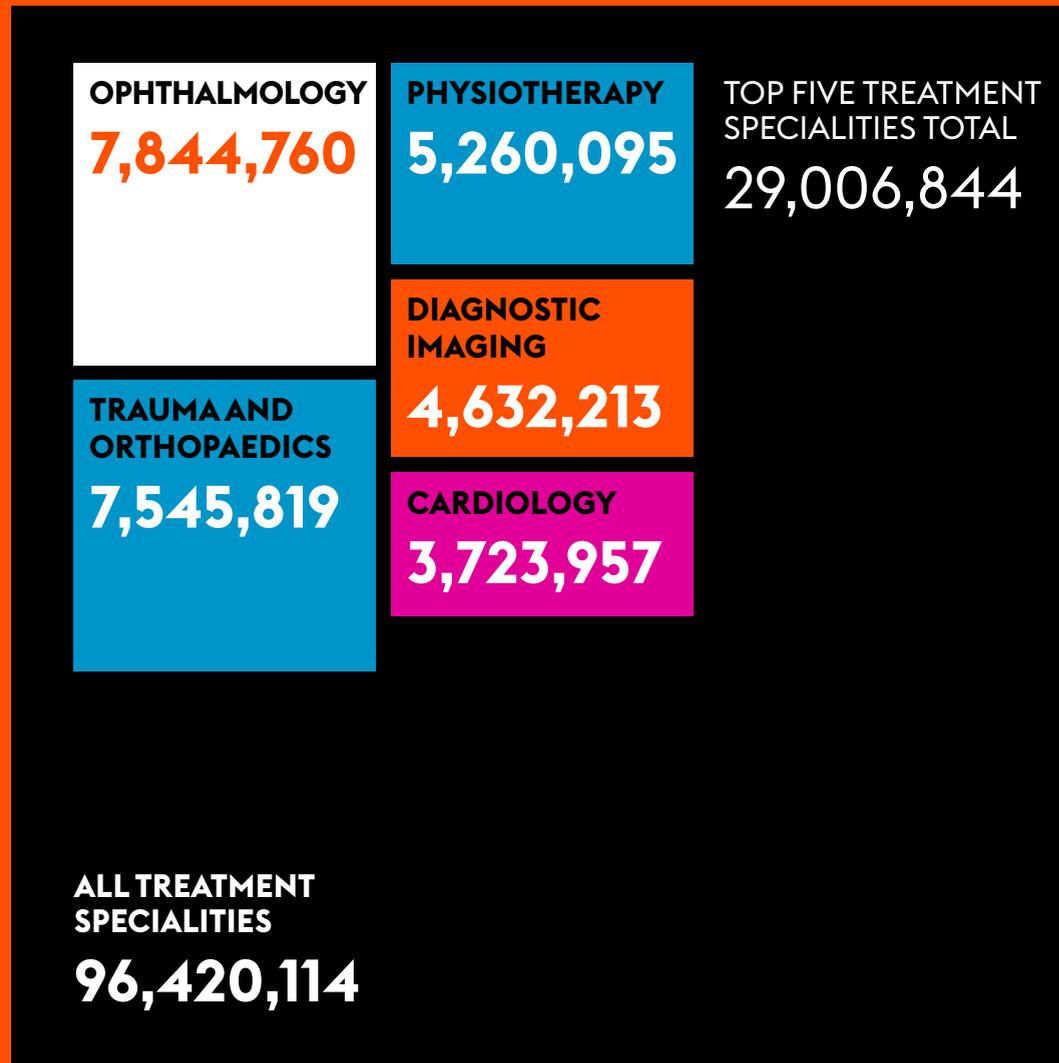
²² Figure derived from our LSE model based on Global Burden of Disease data.

²³ Deloitte Access Economics (2017) Incidence and risk of sight loss and blindness in the UK, RNIB. Available at: www.rnib.org.uk/professionals/knowledge-and-research-hub/incidence-and-risk-sight-loss-and-blindness-uk

UK PREVALENCE OF COMMON EYE CONDITIONS

NOTE: This infographic shows the estimated total number of people living with the most common eye conditions in the UK though data in this area is scarce and needs further investigation.





**OUTPATIENT ACTIVITY
IN ENGLAND
BY ATTENDANCES**

SOURCE: NHS Digital, Summary Report 7, Hospital outpatient activity, 2018-19 digital.nhs.uk/data-and-information/publications/statistical/hospital-outpatient-activity/2018-19



Treating the wide range of eye conditions and caring for people with sight loss is placing enormous strain on the UK's National Health Service (NHS) and social care services.

NHS ophthalmology services are currently struggling and in danger of collapsing under the weight of the ever-increasing demand as our population ages. Today, there are more than a million (1,020,416) people over 70 in the UK living with sight loss.²⁴

One in 10 (10 percent) of all hospital outpatient appointments is for eye services.²⁵ And ophthalmology appointments accounted for the highest number of NHS attendances in England in 2018/19, at 7.8 million.²⁶

NOTES TO TABLES

The figures in Tables 1 and 2 (overleaf) are based on UK Global Burden of Disease data²⁷ which were used, along with condition-specific prevalence data for moderate and severe sight loss,²⁸ in the development of our costing model to ensure a more accurate assessment of the impact and cost of sight loss. It's important to note that because the

condition-specific Global Burden of Disease data measured moderate and severe cases, the total numbers for each condition in the model were significantly lower than the estimated total numbers of people living with each eye condition, shown in the infographic above. All the figures used to create our costing model are available in appendix 3.

²⁷ Global Burden of Disease Injury Incidence Prevalence. Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017. Lancet. 2018; 392(10159): 1789-858. ghdx.healthdata.org/gbd-results-tool

²⁸ Defined in the Global Burden of Disease data as: blindness – visual acuity of <3/60 or <10 percent visual field around central fixation; severe vision impairment – >=3/60 and <6/60; moderate vision impairment – >=6/60 and <6/18.

²⁴ Global Burden of Disease Injury Incidence Prevalence Collaborators (2018) 'Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990-2017: A systematic analysis for the Global Burden of Disease Study 2017', Lancet, 392 (10,159), pp1,789-858. Available at: ghdx.healthdata.org/gbd-results-tool

²⁵ Royal College of Ophthalmologists (no date) The way forward resources. Online. Available at: www.rcophth.ac.uk/standards-publications-research/the-way-forward

²⁶ NHS Digital (2019) Hospital outpatient activity 2018-19. Online. Available at: www.digital.nhs.uk/data-and-information/publications/statistical/hospital-outpatient-activity/2018-19

Table 1:

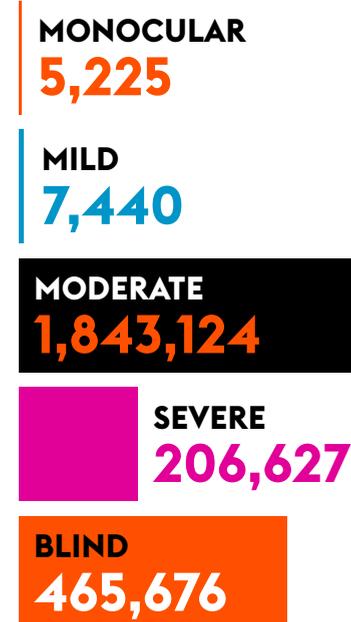
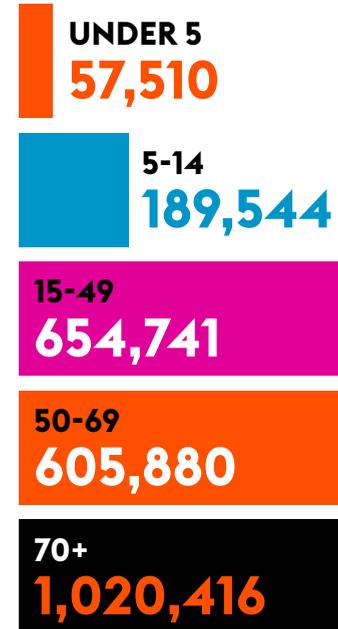
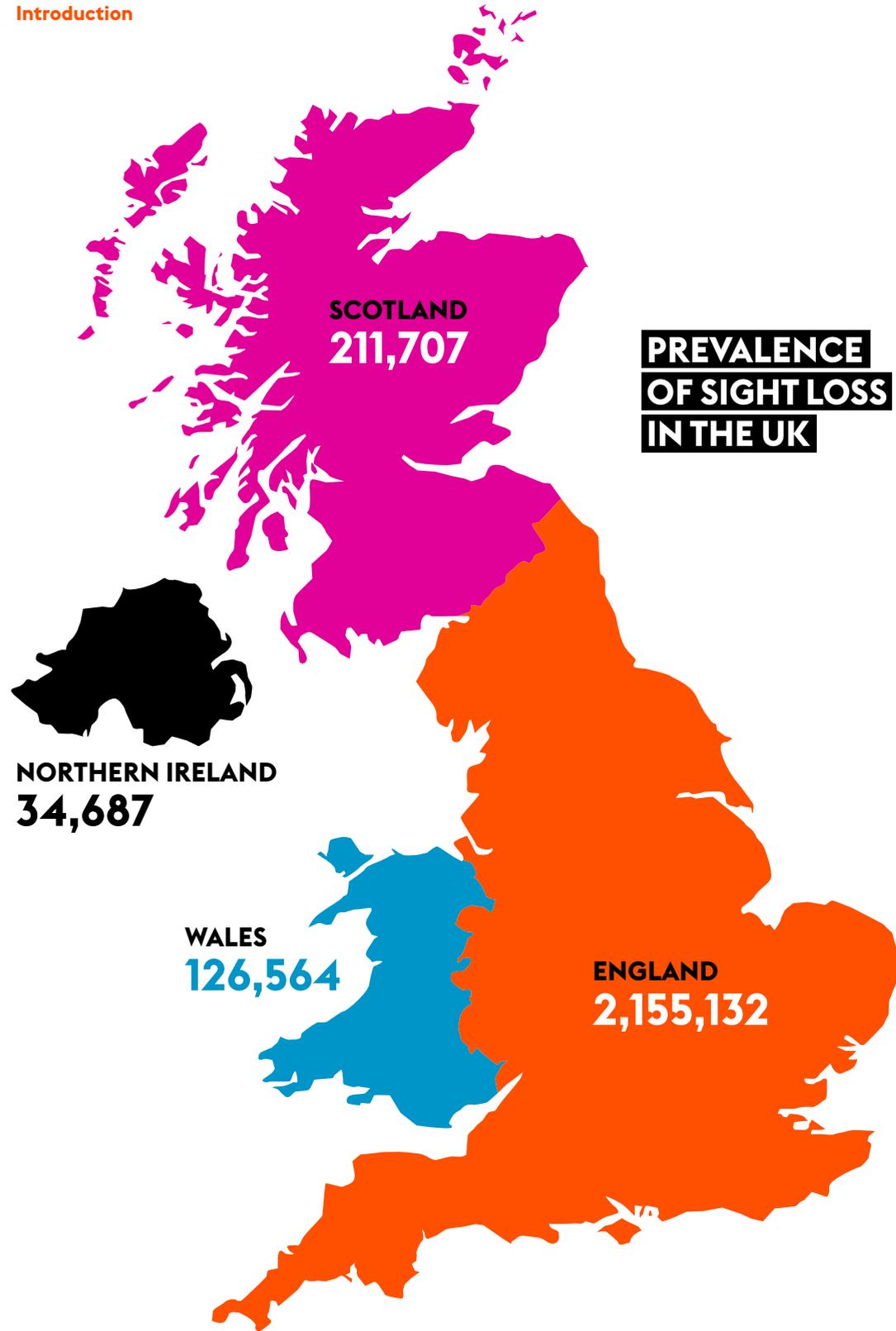
Prevalence of visual impairment, by age and gender, UK, 2017

	Under 5		5-14		15-49		50-69		70+		All ages		All
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	
England	25,611	24,438	84,460	79,483	288,380	272,743	252,719	258,947	343,675	524,677	994,844	1,160,288	2,155,132
Scotland	2,074	1,939	7,284	6,772	26,985	26,577	26,623	28,386	32,867	52,199	95,834	115,874	211,707
Northern Ireland	534	447	1,657	1,340	5,539	4,649	4,344	3,624	5,589	6,965	17,662	17,025	34,687
Wales	1,274	1,192	4,444	4,104	15,388	14,481	15,320	15,916	21,796	32,648	58,222	68,342	126,564
United Kingdom	29,493	28,017	97,845	91,699	336,291	318,450	299,006	306,874	403,927	616,489	1,166,562	1,361,529	2,528,090

Table 2:

Prevalence of visual impairment by severity, UK, 2017

	One eye affected		Mild		Moderate		Severe		Blind		All severity		All
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	
England	2,205	2,187	3,265	3,144	769,060	797,779	78,385	96,979	141,929	260,200	994,844	1,160,288	2,155,132
Scotland	211	224	277	271	74,487	80,654	7,766	9,955	13,092	24,770	95,834	115,874	211,707
Northern Ireland	69	73	96	91	14,879	14,063	1,379	1,535	1,239	1,264	17,662	17,025	34,687
Wales	126	130	152	144	44,983	47,217	4,792	5,837	8,168	15,014	58,222	68,342	126,564
United Kingdom	2,611	2,614	3,791	3,649	903,410	939,714	92,322	114,305	164,428	301,248	1,166,562	1,361,529	2,528,090



Introduction

Today, there is no treatment for around 90 percent of cases of age-related macular degeneration, the leading cause of blindness in the UK. And while we can stop glaucoma progressing if we catch it early enough, we can't undo the damage it has already done.

This is a public health crisis that can no longer be ignored.

Care and support are extremely important for people living with sight loss. But unless we invest more in research, and focus on prevention and early diagnosis, we will never end these conditions or the suffering they cause, only ever manage their effects. With hundreds of eye conditions leading to sight loss, tackling this crisis will take ambition, commitment and investment.

The UK is not alone. Sight loss is a global crisis that demands a global response. **Around the world, at least 2.2 billion people have sight loss or blindness. And at least 1 billion have a condition that could have been prevented or has yet to be treated.**²⁹

“Vision has a significant impact on the health and wellbeing of people across the spectrum of life. It enables children to gain an education, working age adults to get and keep a job, and older people to remain connected to the economic and social fabric of their communities.”

The International Agency for Prevention of Blindness

²⁹ World Health Organization (2019) Blindness and vision impairment. Online. Available at: www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment

PEOPLE WITH
SIGHT LOSS WORLDWIDE
2.2BILLION

THOSE WHOSE SIGHT
LOSS COULD HAVE BEEN
PREVENTED OR HAS
YET TO BE TREATED
1 BILLION

Ensuring universal eye health through early detection, prevention, treatment as well as better access to support and services will contribute directly to the sustainable development goals. There is an urgent need to find quicker diagnoses, better cures and prevent vision loss to ensure better quality of life for those already affected by sight loss and those who are at risk of it.³⁰

Research is vital to find cures and new treatments for sight loss. But eye research is getting a fraction of the investment it desperately needs.

³⁰ Sustainable development goal 3, Target 3.8: Ensure healthy lives and promote well-being for all at all ages. Sustainable development goal 8, Target 8.5: Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all www.iapb.org/advocacy/sustainable-development-goals/

Introduction

In 2018 UK Research and Innovation, government, charities and other public bodies invested £1.4 billion in medical research. Just over 1.5 percent (£24 million) of that was for eye research,³¹ compared with 2.6 percent for respiratory diseases, 9.6 percent for neurological conditions (including dementia, Alzheimer's and Parkinson's), and 9 percent for cancer and neoplasms.³²

This is despite many other conditions having lower prevalence than sight loss, in particular dementia, which is also a disease associated with old age and currently reports prevalence levels that are less than half those of sight loss.³³

To put this number in context, this is just **£9.60** being spent on research for each person affected by sight loss in the UK.

“It’s not funded. For reasons that are not entirely clear, because the public certainly care very much about the prospect of losing their sight, the government doesn’t seem to be that bothered about vision and eye health. They’re not giving us the same percentage investment in research and development as other specialities in other areas. Which just demonstrates that it’s not a priority for them.”

Sight loss professional

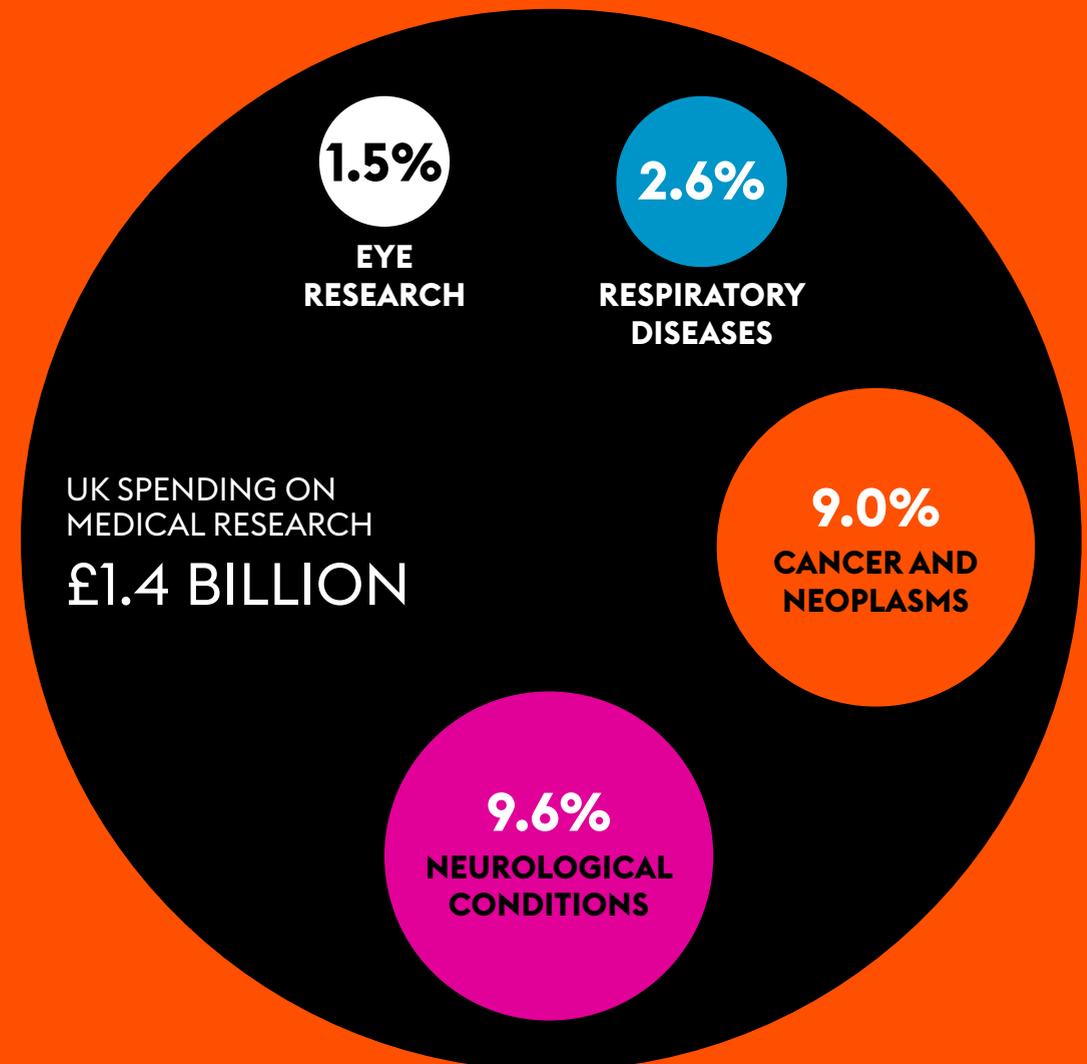
And in addition, across the sight loss sector, just three percent of spending (£12.5 million) was on research, with the vast majority being spent on care and support for people with sight loss.³⁴

^{31, 32} Calculated from UK Health Research Analysis 2018 (UK Clinical Research Collaboration, 2020) hrcsonline.net/reports/analysis-reports/uk-health-research-analysis-2018/

³³ The Alzheimer's Society reports 850,000 people are living with dementia in the UK in 2020. www.alzheimers.org.uk

³⁴ A Fight for Sight figure calculated from the proportion of income invested in eye research in 2018 from the top 16 sight loss charities: Blind Veterans, Catholic Blind Institute, Deafblind UK, Fight for Sight, Guide Dogs for the Blind, Macular Society, Moorfields Eye Charity, National Eye Research Charity, RNIB, Royal Blind School, Scottish War Blinded, Seeability, Sense, The Royal Society for Blind Children, Thomas Pocklington Trust, WESC Foundation.

UK PUBLIC BODY SPENDING ON MEDICAL RESEARCH



On top of this lack of investment, Covid-19 has shifted already limited resources and funds away from eye research. Nine in 10 of the researchers we surveyed were forced to suspend their work (see appendix 6), either because their labs were closed or they were sent to the frontline against the virus. All our researchers now face unexpected costs to keep their ground-breaking work going. And nine in 10 respondents believe future research funding has become uncertain because of the pandemic.³⁵

So, why is sight loss research so underfunded?

One reason is that most people don't know sight loss can be prevented or cured. They mistakenly think that sight loss equals blindness and is therefore unavoidable and untreatable.

This lack of awareness of the causes and treatments of sight loss is robbing people of their vision and quality of life.

It is estimated that more than a million people in the UK are living with avoidable sight loss.³⁶ This is an injustice that must be corrected.

³⁵ The impact of Covid-19 on sight loss research has also been highlighted by the Royal College of Ophthalmologists in its paper *Mitigating the impact of Covid-19 on Academic Ophthalmology and Ophthalmic Research*. bit.ly/30mvV2O

³⁶ Based on IAPB Vision Atlas figures. atlas.iapb.org

**ONE
MILLION** PEOPLE IN THE UK
LIVING WITH AVOIDABLE
SIGHT LOSS

Sight loss is not inevitable.

Through pioneering eye research we can transform the lives of people with sight loss and relieve the strain on the NHS and social care services. This is an exciting time to be involved in eye research as progress in our understanding of genetics, genes and immunology over the last few years has the potential to completely change the way we treat and manage many eye conditions.

As the UK's leading charity dedicated to funding pioneering eye research we have made possible transformational treatments for inherited eye disease (see page 110), a new gene therapy for glaucoma (page 113), and a new technique for treating a type of Leber congenital amaurosis (page 113).

However, with people across the UK and globally living with hundreds of eye conditions, there is no easy solution to the enormous challenge we face. It is vital we learn more about the varied causes of sight loss and how we can treat, and ultimately cure, these conditions.

In 2019 the World Health Organization and United Nations General Assembly highlighted that more investment is needed in sight loss research globally, calling for each nation to have a coordinated plan to tackle sight loss.

We must urgently come together – government, health services, businesses, charities and researchers – to act on this public health crisis and create a world everyone can see.



A CLEARER PICTURE OF SIGHT LOSS

Our research findings



As a leader in the fight against sight loss, we brought together sector partners, academics and people with eye conditions to find out how best to catalyse action.

Through these discussions it became clear that a more complete picture of sight loss in the UK was needed. This would enable decision makers to understand the real impact on people's lives, the true cost of this public health crisis and the potential of research to transform lives.

To achieve this ambitious goal we led new insight into four areas:³⁷

- qualitative and quantitative surveys of almost 800 people living with eye conditions, their families and carers, and our partners across the ophthalmology and charity sectors, to reveal the impact of eye conditions on all areas of life
- a comprehensive systematic literature review and prevalence-based economic modelling, to more accurately estimate the costs of sight loss to the UK economy (including follow-up analysis on the economic impacts of Covid-19)
- a bibliometric analysis (using statistical methods to analyse research publications), to assess the impact of UK sight loss research
- surveys to understand the impact of the coronavirus pandemic on both people with eye conditions and sight loss researchers³⁸

Together these areas of insight give us a clearer picture than ever before of the impact of sight loss and the scale of the challenge to be met. They present campaigners and decision makers with a credible and comprehensive source of evidence.

This definitive report focuses on the most urgent findings. It puts forward recommendations for the UK and devolved governments, health services, industry and charities. And it makes the case for significantly increasing funding for sight loss research to transform lives.³⁹

³⁷ Most of the work was carried out in 2019 and early 2020, before the coronavirus pandemic.

³⁸ Our research into the impact of Covid-19 has been published: Ting D, Krause S, Said D, Dua H (2020) 'Psychosocial impact of Covid-19 pandemic lockdown on people living with eye diseases', Eye, published online, www.nature.com/articles/s41433-020-01130-4

³⁹ You can read the full insight reports in the appendices.

OUR METHODOLOGIES⁴⁰

KALEIDOSCOPE RESEARCH

first carried out qualitative phone interviews with six Fight for Sight stakeholders, including partners, researchers and decision makers, and 12 people affected by sight loss.

These findings informed quantitative online and phone surveys of 749 people living with eye conditions (including 37 parents and 90 carers of people with eye conditions) at the beginning of 2020. The data is unweighted, as no UK population targets for people with eye conditions are available, but the sample is robust enough for the results to be meaningful. The sample profile is broadly in line with expectations based on UK-wide age/gender skews and the more prevalent conditions. It is also similar to the UK profile for regional representation/type of area.

THE LONDON SCHOOL OF ECONOMICS AND POLITICAL SCIENCE (LSE), led by Associate Professor David McDaid and Assistant Professor A-La Park, carried out a comprehensive literature review of studies (from any high-income country) looking at the costs of visual impairment.

This included costs to the health sector, other sectors of the economy, such as social care and education, out-of-pocket costs to people living with visual impairment, time out of work, the need for informal unpaid care, administrative costs of welfare benefits, and reductions in quality of life. It examined

economic evaluations of interventions to prevent or treat visual impairment compared with the costs of not acting.

The review was used to develop a model to estimate the costs of visual impairment and blindness to the UK health and social care system and beyond (more information on the model can be found on page 64 and in appendices 3 and 4).

First a prevalence-based approach was used to measure the number of people living with visual impairment and estimate the average costs associated with these conditions over one year. This was based on 2017 UK data from the Global Burden of Disease, focusing on moderate and severe sight loss, and using costs derived from the literature review.⁴¹

Secondly, incidence-based costing was used to estimate the lifetime impacts of visual impairment for glaucoma and age-related macular degeneration, to illustrate the potential economic benefits of prevention and early intervention.

Both methodologies were used to produce separate cost estimates, first of the current impacts of sight loss, and secondly the long-term projected costs and how much could be saved by reducing prevalence over a certain time period through prevention and treatment strategies. Projections were reported using the same price year, to give the 'real' increase in projected costs rather than the 'nominal' increase in costs.

The researchers then used data from our quantitative survey of people with sight loss to look at quality of life and loneliness in people with various levels of visual impairment and conditions. Finally, they considered what some of the economic impacts of the coronavirus pandemic may be, drawing on their insight to identify where there may be additional economic costs.

CLARIVATE used the Web of Science, a database of research publications, to identify a total of 548,342 eye-related publications using three methods: journal subject categories, medical subject headings and keyword searches.

It then identified where researchers cited (referred to) earlier publications used in the course of their own work. It considered a publication among the world's top 10 percent of the most highly cited papers in the publication year and field to which it relates

as being highly cited. If a publication had more than one author, this was an indication the research was the result of more than one person's effort. Funding acknowledgement data was used to identify papers supported by Fight for Sight and other agencies.

FIGHT FOR SIGHT carried out two further online surveys to understand the impact of the coronavirus pandemic, firstly on people with eye conditions (325 respondents) and secondly on sight loss researchers (39 respondents).

For the first survey, there was a female skew (73 percent) and 66 percent of respondents were aged 65 or older. Sixty five percent of respondents had moderate or severe sight loss. While the second survey sample was not big enough to provide robust data, it offered a useful insight into the impact of the pandemic on Fight for Sight funded research.

The report is accompanied by a new costing tool, based on our systematic literature review, that provides decision makers with UK Global Burden of Disease sight loss prevalence data and the cost of treatment and services (see page 64 and appendix 4). Government, funding bodies and health service commissioners and providers can also for the first time adjust the values of parameters to estimate more accurately the cost of future prevalence in their area. The model demonstrates how investing in sight loss research and prevention could transform lives and protect the UK economy.

⁴⁰ See the appendices for more detail on the methodologies.

⁴¹ Our studies revealed that there are limitations to the currently available prevalence data for eye conditions in the UK. While the Global Burden of Disease 2017 data utilises a number of vision loss survey sources, these may not be comprehensive and may have

inherent limitations and self-report bias. At the time of finalising this report The Vision Loss Expert Group and Global Burden of Disease Study are updating this data. Our costing model, which will be freely accessible, has been designed to incorporate the latest data to allow a more up-to-date real-time analysis.

THE COSTS OF SIGHT LOSS

The extensive review of 351 studies on both the costs of visual impairment and its wider consequences in the UK and beyond is one of the most comprehensive sight loss literature reviews to date. This has informed the development of a new costing tool that gives us a more accurate picture than ever before of the true cost of sight loss in the UK. The model has also been used to estimate the potential future costs of sight loss.

This new insight has revealed a staggering total cost to the UK economy of **£25.2 billion** a year. That's more than the combined annual expenditure of both the Home Office and Ministry of Justice. And using our costing tool, we estimate this will rise to **£29.9 billion** a year by 2030 and **£33.5 billion** a year by 2050.

No UK country or region escapes the impact of sight loss, with all carrying a significant economic cost.

Our study has revealed that 84 percent of the economic costs of sight loss lie outside the health and social care system, reflecting the costs of informal care by family and friends, productivity losses and quality of life impacts, and highlighting the far-reaching impacts on the UK economy.

DEVICES
589,832

INFORMAL CARE
8,458,657

WELFARE ADMIN
111,095

QUALITY OF LIFE COSTS
4,628,676

HEALTH AND
SOCIAL CARE
3,943,038

PRODUCTIVITY
7,411,818

EDUCATION
107,845

**COST OF VISUAL
IMPAIRMENT IN THE
UK BY TYPE OF COST**
(£000s)

⁴² Health and social care costs include all eye-related hospital activity for inpatient and day-case procedures, as well as outpatient care and hospital-prescribed medications; education includes costs to the sector for children classified as blind; devices includes low vision aids and adaptations (but not guide dogs) to help maintain independence; productivity relates to the exclusion from the workforce of people of working age; welfare admin represents the administrative costs associated with managing welfare benefits received by individuals of different ages, including both those who are and are not registered for visual impairment or blindness (it does not include the value of the welfare benefits themselves as these are considered to be a transfer payment rather than a cost); informal care refers to care provided by family and friends, valued using average hourly wage rates; and quality of life losses are approximated here by placing a monetary value on the disability adjusted life years associated with visual impairment, and excluding productivity costs to avoid potential double counting.

Table 3:

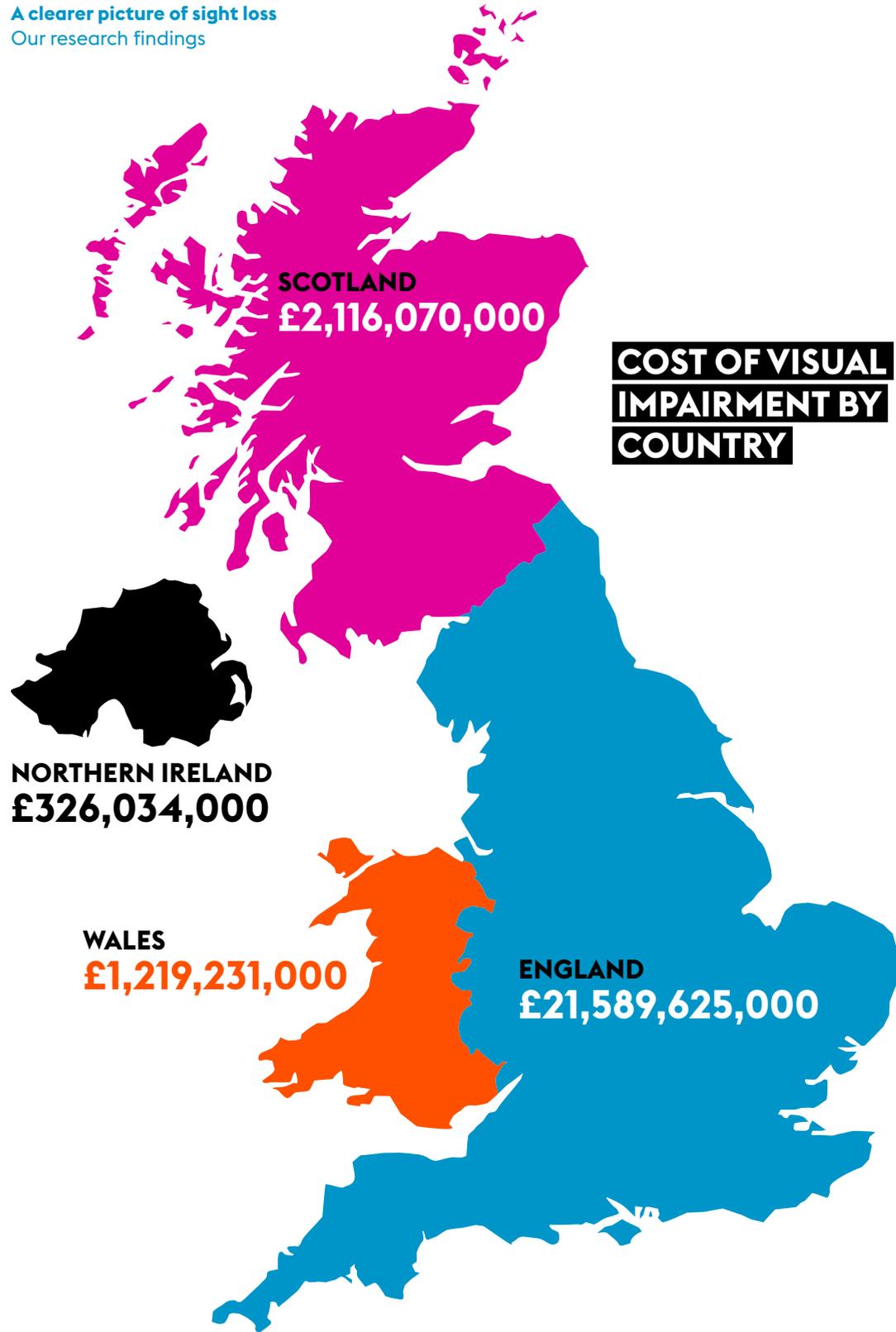
Total costs of visual impairment in the UK in 2017 (2019 prices) (£000s)⁴²

	Health & social care	Education	Devices	Productivity	Welfare admin	Informal care	Quality of life	All costs
England	3,361,166	93,931	502,801	6,361,146	94,691	7,210,563	3,965,327	21,589,625
Scotland	330,331	8,084	49,411	630,934	9,501	708,597	379,211	2,116,070
Northern Ireland	53,933	949	8,073	98,943	1,632	115,772	46,731	326,034
Wales	197,608	4,880	29,547	320,795	5,270	423,724	237,406	1,219,231
United Kingdom	3,943,038	107,845	589,832	7,411,818	111,095	8,458,657	4,628,676	25,250,960
Percent of total costs	15.62%	0.43%	2.34%	29.35%	0.44%	33.50%	18.33%	

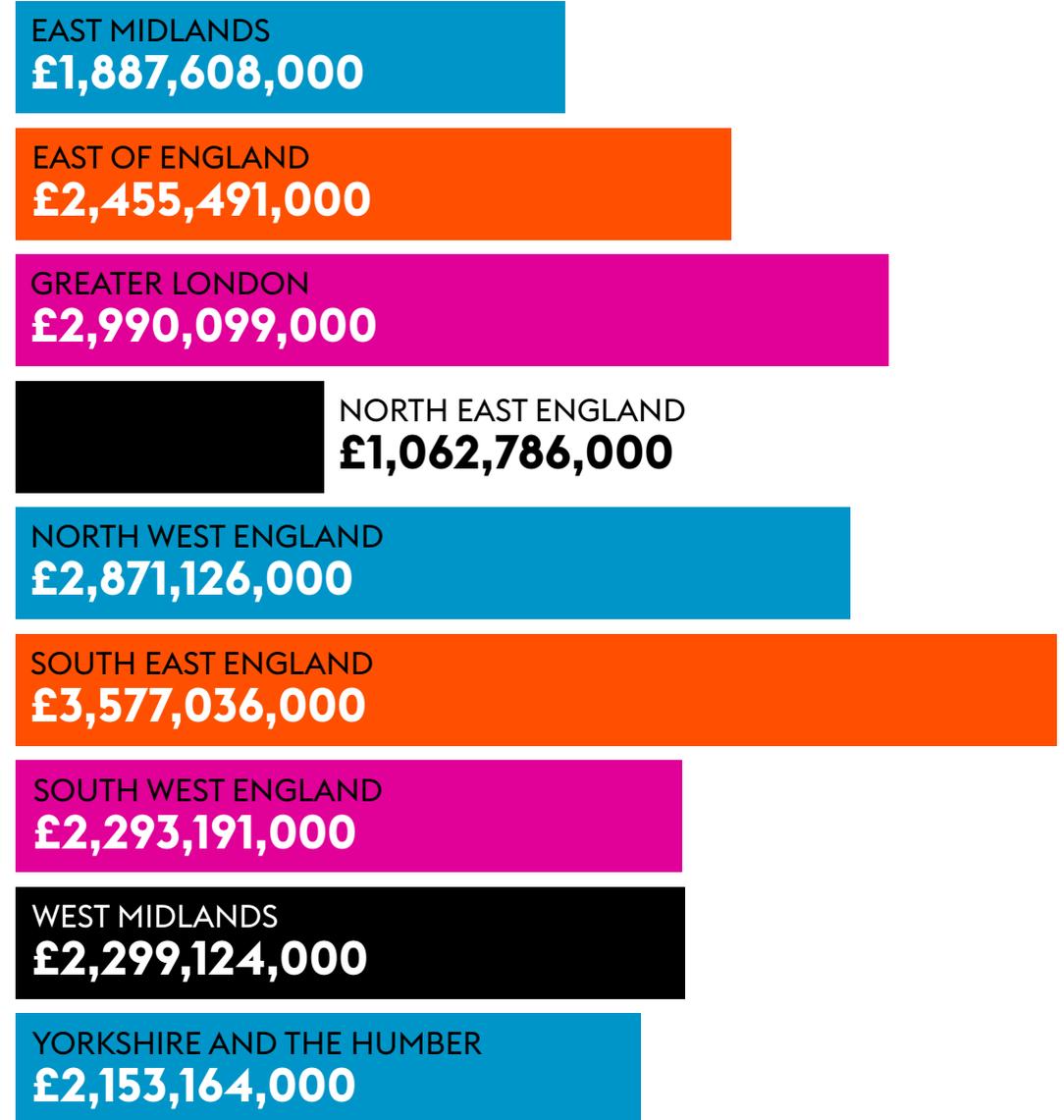
Table 4:

Total costs of visual impairment in English regions in 2017 (2019 prices) (£000s)

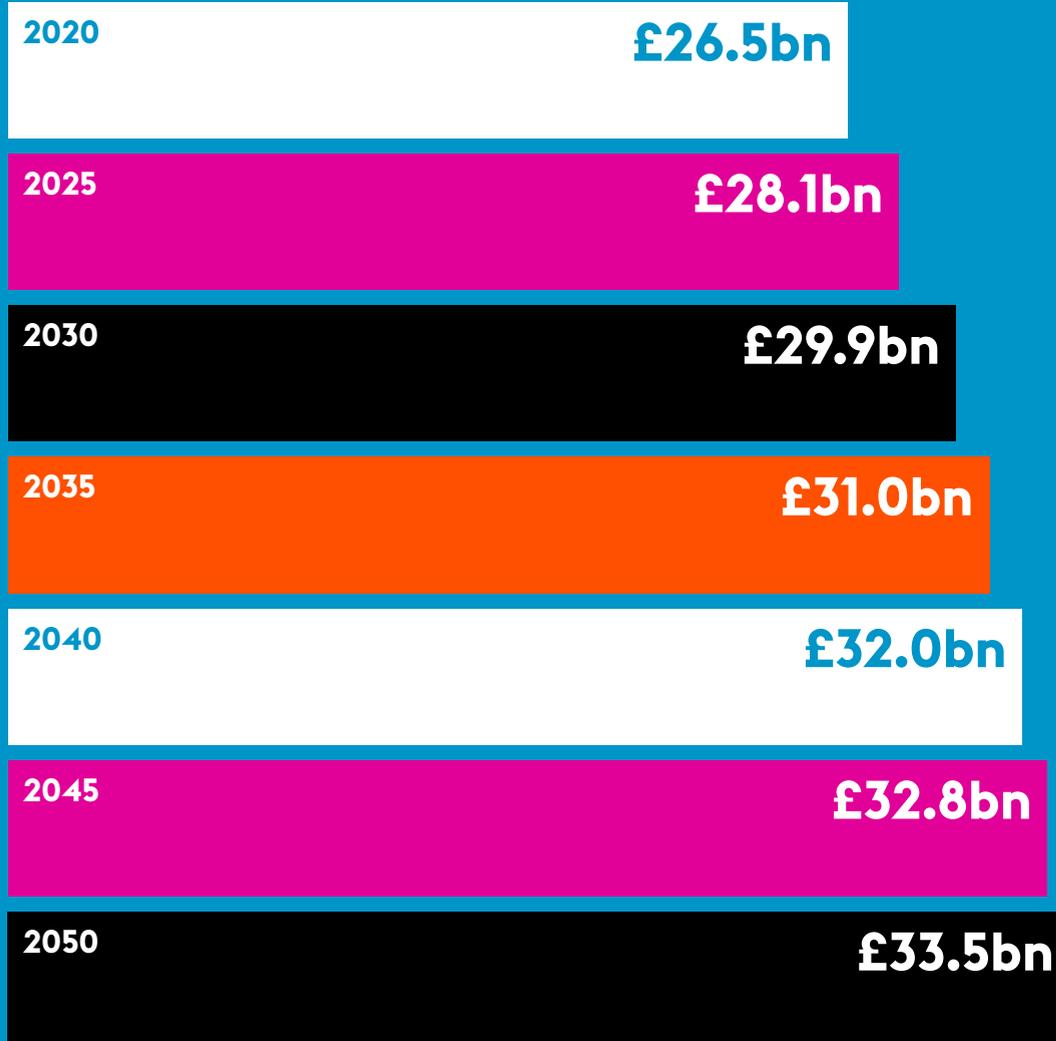
	Health & social care	Education	Devices	Productivity	Welfare admin	Informal care	Quality of life	All costs
East Midlands	295,035	7,851	44,126	546,703	8,136	632,808	352,948	1,887,608
East of England	386,214	10,098	57,755	694,366	10,331	828,245	468,481	2,455,491
Greater London	447,738	15,845	67,085	1,032,884	15,384	962,053	449,110	2,990,099
North East England	166,206	4,266	24,857	308,178	4,590	356,473	198,215	1,062,786
North West England	446,613	13,059	66,807	843,102	12,552	958,063	530,930	2,871,126
South East England	560,885	14,669	83,881	1,019,328	15,168	1,202,923	680,182	3,577,036
South West England	363,269	8,297	54,300	619,743	9,225	778,708	459,650	2,293,191
West Midlands	359,583	10,448	53,785	664,131	9,885	771,312	429,979	2,299,124
Yorkshire and the Humber	335,622	9,397	50,205	632,711	9,419	719,978	395,831	2,153,164
Total	3,361,166	93,931	502,801	6,361,146	94,691	7,210,563	3,965,327	21,589,625



COST OF VISUAL IMPAIRMENT BY ENGLISH REGION



PROJECTED COST OF VISUAL IMPAIRMENT IN THE UK



With the health and social care sector struggling to meet the demands of sight loss, the reliance on family and friends to fill the gaps in services has a significant economic cost. We estimate this ‘informal’ care is costing the UK economy £8.5 billion a year – a third of the total cost – although there is little information on the financial impact on carers, so the actual figure is likely to be much higher.

Despite disability legislation a high number of working-age people are excluded from the workplace because of their eye condition, citing accessibility and employer attitudes as issues. These barriers to productivity are costing the UK economy up to £7.4 billion – nearly another third of the total costs.

And the impacts of sight loss on people’s quality of life accounts for up to £4.6 billion – almost a fifth of the total costs.⁴³ This is a conservative estimate of the economic costs of the negative impact of eye conditions on people’s lives.

However the health and social care costs alone are massive. **Today, treating sight loss is costing the NHS and social care services up to £3.9 billion a year.**

The remaining costs are derived from education costs, welfare and devices, as outlined in Tables 3 and 4.

Sixty three percent of the health and social care costs are related to hospital activity – for inpatient and day surgery, as well as outpatient care. Community general ophthalmic services and pharmaceuticals account for 21 percent. Mental health services associated with visual impairment make up five percent. And specialist short-term and long-term home and residential care account for five percent of the costs.

The three most prevalent eye conditions are age-related: cataracts, glaucoma and age-related macular degeneration.

⁴³ Approximated by placing a monetary value on the disability adjusted life years associated with visual impairment and excluding productivity costs to avoid potential double counting.

Treating these conditions is costing the NHS and social care services £2 billion a year (cataracts £689 million, glaucoma £94 million, age-related macular degeneration £1.2 billion). And this figure is rising with our ageing population.

“One of the absolute key issues is the forecast growth in the number of people who are likely to experience sight loss in the future. ...really extraordinary growth over the next 10 to 15 years linked to the fortunate situation that we are generally, as a population in the UK, living longer.”

Sight loss professional

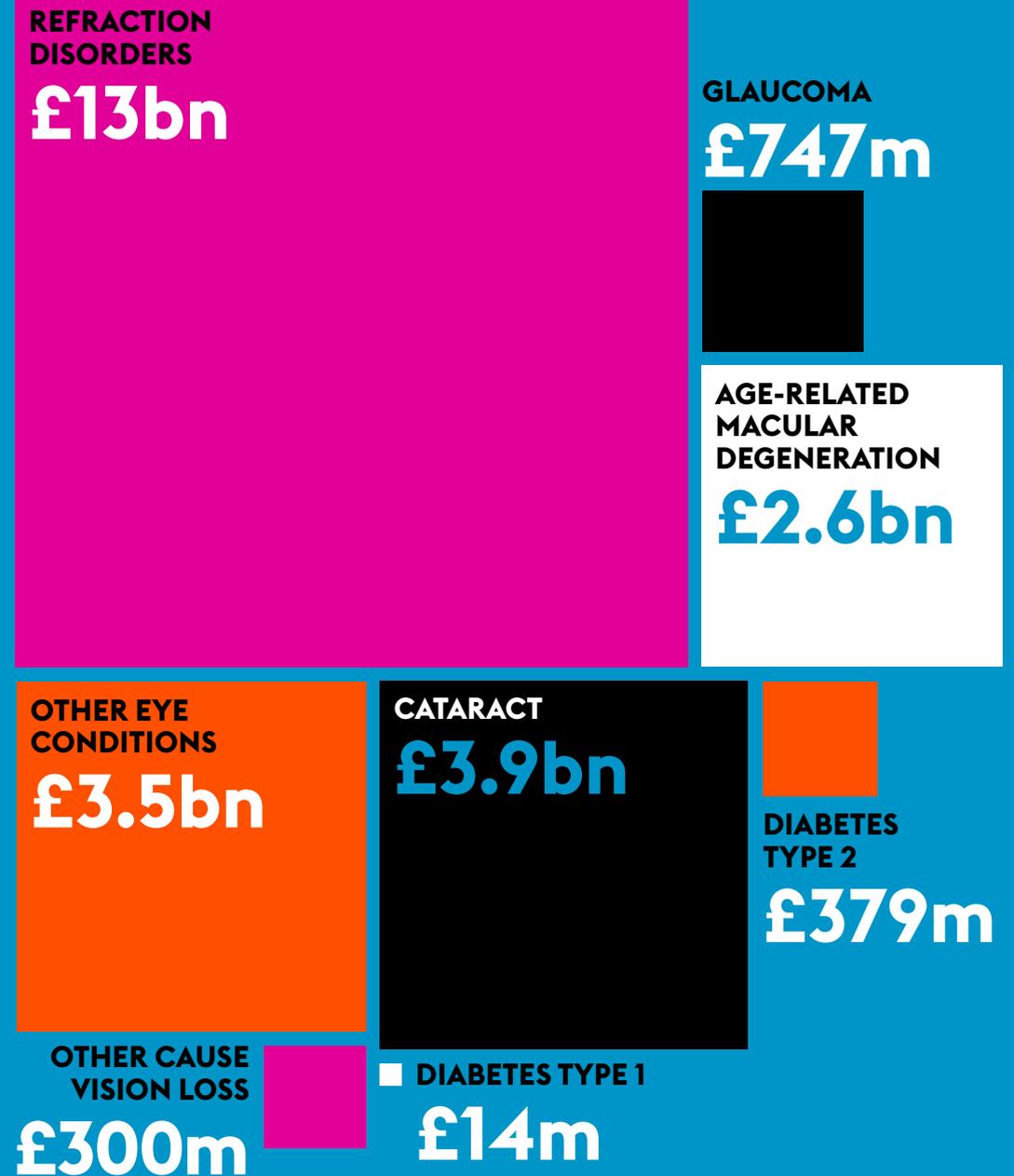
Including the wider societal costs of the most common eye conditions reveals the scale of the economic impact of this public health crisis.

- Each year, age-related macular degeneration costs the UK economy £2.6 billion – over half of which (53 percent) falls outside health and social care.
- For cataracts, the annual cost is £3.9 billion – 82 percent of which is beyond the health and social care system.
- And glaucoma costs the UK £747 million a year – 87 percent of which lies outside health and social care.

These are not the only eye conditions with a significant economic impact.

Diabetic retinopathy has an annual cost of £379 million (51 percent non-health and social care) for cases linked to type 2 diabetes, and almost £14 million for cases related to type 1 diabetes (56 percent non-health and social care).

TOTAL COSTS OF VISUAL IMPAIRMENT BY CAUSE



OUR PREVALENCE-BASED COSTING MODEL

Our new costing tool, developed by academics at LSE, for the first time provides decision makers with the information they need to model sight loss prevalence and the cost of treatment and services.

The model enables projections to be made based on a comprehensive review of the sight loss literature and Global Burden of Disease sight loss prevalence data for the UK.

As the model is based on Global Burden of Disease data for moderate to severe cases of sight loss, it gives an indication of where interventions can have most impact. As these are lower figures than the total prevalence of each condition and do not account for inflation to show 'real' rather than nominal increases in cost, our projections are likely to be underestimates of the true costs. Importantly, we include costs beyond the health sector, such as informal care, which our insight shows make up the biggest proportion of the economic impact.

Flexible parameters enable different scenarios to be played out and their impacts on the UK

economy estimated. For instance, epidemiological assumptions can be changed on the prevalence and/or incidence of different types and severities of visual impairment by gender and age, resource requirements and costs associated with the provision of care and other support, and the likelihood of people being in employment or receiving informal care.

In addition to UK-wide estimates, decision makers can focus on any one of the four nations of the UK or a more local level.

The model makes it possible to estimate the change in potential economic costs associated with changes in the prevalence of sight loss, for example, estimating the economic value of a one percent reduction in visual impairment. With this information, decision makers can assess the cost effectiveness of investing in interventions to prevent or reduce the impacts of visual impairment.

The tool is open access. Download it today along with our full research findings at www.fightforsight.org.uk

Refractive disorders, while outside the focus of Fight for Sight and pioneering sight loss research, are the most common cluster of causes of correctable visual impairment in the global burden of disease for the UK – by far the greatest contributor to the overall cost at £13 billion.

Other eye conditions add up to a cost of £3.5 billion – 79 percent of which lies outside health and social care. Most of this is related to the impact on people over 50, but there are further impacts on younger people, often related to refractive disorders, including myopia, as well as for a number of neonatal disorders.

Significantly the quality of life-related costs of vision loss due to complications at birth and other neonatal disorders are, in fact, greater than the burden of glaucoma. We estimate there are costs in excess of £300 million for visual impairment mainly caused by non-eye-related disorders, including neonatal disorders that result in sight loss to the child. More needs to be done to look specifically at the costs of these causes of visual impairment.⁴⁴

Estimates from our new costing model show that if we reduce the prevalence of eye conditions by just one percent each year we could make a cumulative saving to the UK economy of up to £3 billion over the next decade and £9.5 billion by 2050. This would save NHS and social care services a potential £1.5 billion.

⁴⁴ This is mainly due to the extra costs of education support in childhood (36 percent), lost employment opportunities (45 percent) and extra informal care (13 percent). This figure underestimates costs as it does not include healthcare costs, and only a limited amount of social care and device-related costs. This assumes the UK working age is 18-67, with expected life expectancy of 80 years for men and 83 years for women.

RECOMMENDATION

Health service commissioners and providers must better understand the impact of neonatal health on sight loss – to reduce the substantial quality of life costs of associated visual impairment and transform the lives of children and parents.

For the first time, our new costing tool also allows us to estimate the impact on the UK economy of sight loss over an individual's lifetime, including the conditions age-related macular degeneration and glaucoma – two leading causes of sight loss in the UK.

The costs for a hypothetical individual show that the expected annual cost per case for visual impairment in the UK is **£9,988**, including 34 percent in informal care costs, 30 percent lost working opportunities, 18 percent lost quality of life and 16 percent health care costs.

The lifetime cost of a new case of age-related macular degeneration in an adult aged 50 or over, causing at least moderate visual impairment, is £73,350, while the lifetime cost of glaucoma is £49,800 per person. Reducing the prevalence of these conditions by just 14 or 20 cases respectively could save the UK economy £1 million in lifetime costs.

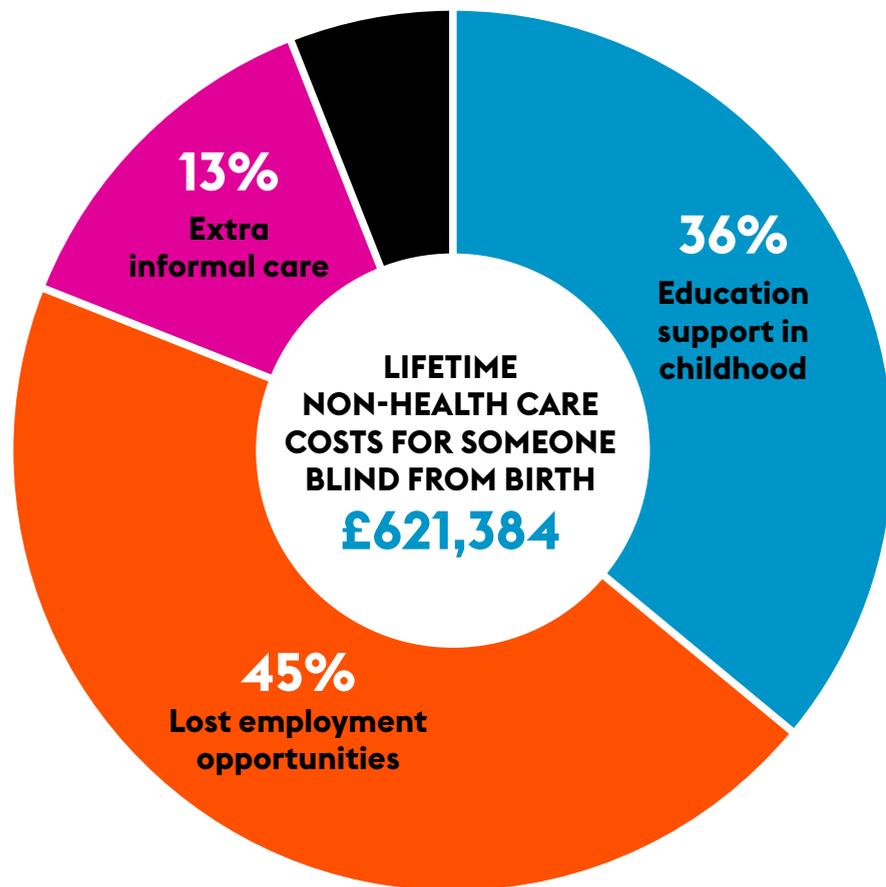
It's notable that the NHS bears a much higher share of the costs for age-related macular degeneration, due to the high costs of treatment compared with glaucoma. Glaucoma affects more people of working age, so there are higher costs due to reduced productivity but not to the health sector.

A conservative estimate for the remaining lifetime non-health care costs for blindness by age 70 is £25,629.

This again is a very conservative figure as it does not include additional health care costs and only limited social care costs. Seventy percent of this estimate of costs is for family care. It also does not include impact of lost quality of life.

The lifetime non-health care cost of sight loss for someone blind from birth is conservatively estimated as £621,384.

This is mainly due to the extra costs of education support in childhood (36 percent), lost employment opportunities (45 percent) and extra informal care (13 percent). This figure underestimates costs as it does not include health care costs, and only a very limited amount of social care and device related costs. This assumes that the UK working age is 18 to 67, with expected life expectancy of 80 years for men and 83 years for women.



RECOMMENDATION

The government and other funding bodies as well as health service commissioners and providers are encouraged to use our prevalence-based costing model – to plan for the future and ensure sight loss research and services are properly funded.

Covid-19 is adding to these costs. Using our glaucoma incidence model we estimate that for every 100 people aged 50 to 54 with probable glaucoma who are identified and treated up to a year late due to difficulties accessing regular eye health checks, five more people will progress earlier than anticipated to moderate visual impairment, adding up to an additional cost to society of £28,098 a year.⁴⁵ Applied to the thousands of cases of people diagnosed with glaucoma each year, this represents an enormous additional cost to the health service.

Before the pandemic, in January 2020, a healthcare regulator reported that each month 22 people with glaucoma were going blind because of delays to their treatment.⁴⁶ This unacceptable situation can only have been made worse by coronavirus. During lockdown, all but emergency treatments were postponed, building a massive back-log and likely leading to a rationing of care.

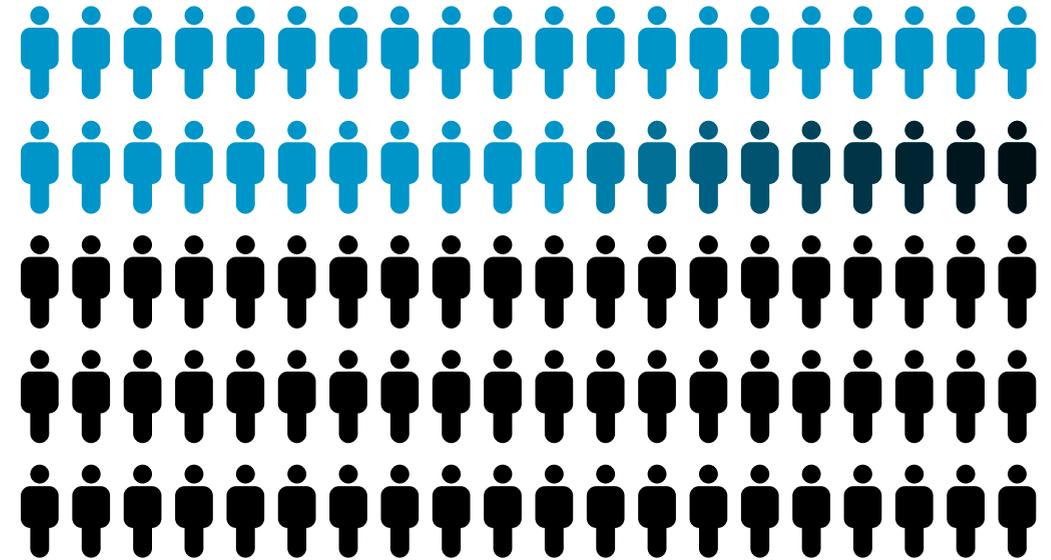
FUTURE COSTS

Our costing tool can be used to model how the costs of sight loss will change in the future, depending on variable outcomes, giving decision makers the ability to see the tangible economic impact of their interventions in the leading causes of sight loss.

While our ageing population means there is a steadily rising tide of people living with sight loss, it's not only older people who are affected. Our survey of people with eye conditions showed that between 31 and 40 percent of people living with retinal, neurological and corneal conditions are under 45 years of age, meaning they will continue to need healthcare support for decades. This will have a significant impact on the economy.

⁴⁵ Based on past studies that have suggested there is a five percent difference in the rate of progression from mild to moderate visual impairment per year if an individual is treated compared with an individual that is not treated.

⁴⁶ www.hsib.org.uk/investigations-cases/lack-timely-monitoring-patients-glaucoma/



31-40% of people living with retinal, neurological and corneal conditions are under 45 years of age

A clearer picture is therefore beginning to emerge. Our results show the huge and wide-ranging costs of sight loss – to the health service and beyond – and demonstrate the economic benefit of investing in prevention and research to reduce the prevalence of eye conditions that cause sight loss or blindness.

These figures show the vast savings that can be made by preventing or stopping blindness at an early stage – through investment in research for new treatments or other prevention measures - and more importantly the huge impact that such interventions have on the quality of life for people living with eye conditions.

THE PERSONAL IMPACTS OF SIGHT LOSS

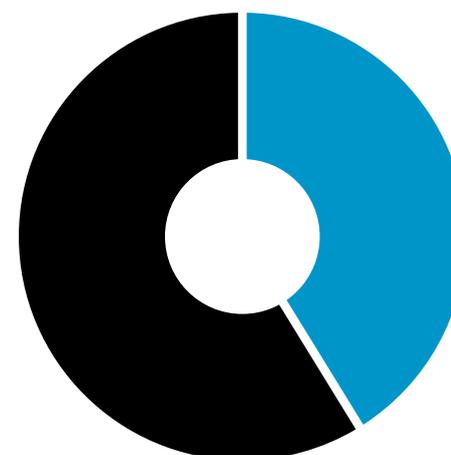
Our insight from surveys of almost 800 people living with eye conditions (83 percent), their families (five percent) and carers (12 percent) makes it clearer than ever how sight loss affects all areas of life. It demonstrates the extent of the personal impact of sight loss on people with eye conditions, their families, carers and the whole of society. And the more severe the sight loss, the greater the negative impact.

FINANCES AND EMPLOYMENT

Sight loss has a significant financial impact on people living with eye conditions. **Of the people we surveyed, two in five (41 percent) feel their conditions have a negative impact on their financial security.**

As expected, the biggest financial impact is on people of working age (18 to 64) (54 percent). This is a result of increased outgoings (29 percent) and a decrease in household income (26 percent).

“You’ve got to pay for your prescriptions, which is quite a lot in my case ...and then I have to pay the NHS cost for my lenses.” [Male \(under 65\)](#)



41%

feel that their conditions have a negative impact on their financial security

A quarter of people (25 percent) feel they are struggling financially as a household. And an even greater proportion (37 percent) of those of working age are under financial stress.

“My best friends – one’s a plumber, one’s a mechanic – they’re earning double what I’m earning, but I can’t do a trade because of my eyesight.” [Male \(under 65\)](#)

Our insight makes clear the impact of eye conditions on people’s access to the workplace. **Almost two in five (37 percent) of those of working age with severe sight loss are not working due to their eye conditions.**⁴⁷

⁴⁷ Based on a small sample size. See appendix 2 for details.

WHO WE HEARD FROM

At least half of the people living with eye conditions who we surveyed have moderate or severe sight loss (53 percent to 74 percent, depending on the condition). Interestingly, almost a third of people (29 percent) have more than one eye condition and over two thirds (69 percent) are living with another health condition.

Our respondents included a greater proportion of females and older people than

the UK population, particularly for age-related conditions. There were also more people from lower-income households in our survey sample than the UK average. Just four percent were Black, Asian and Minority Ethnic compared with a UK average of 14 percent, so more needs to be done to understand the specific impacts of sight loss on people identifying as BAME.

RECOMMENDATION

Government and policy makers must remove the barriers people with sight loss face – to enable them to access education and employment, transport and services in order to support themselves financially. This will require changing attitudes among employers, raising public awareness, and enforcing accessibility requirements.

Among all those who are not working due to their eye condition the main barrier is accessibility (78 percent) such as a lack of suitable jobs (53 percent) or difficulty travelling to work (33 percent).

“I cannot get promoted in my current job, as the only promotion I could go for would be in head office, which is 50 miles away, and I could not get there independently or without a major cost implication. The company can’t find a way to get rid of me, but I do know they would love it if I resigned and saved them so many problems.” Male (45 to 64)

Other barriers include mental ill health and anxiety linked to eye conditions (35 percent), a lack of support (30 percent) and negative attitudes of employers and fellow employees (28 percent).

“My employer has not been fully supportive of my difficulties and has only recently (after six years in my job) accepted that reasonable adjustment to my working conditions is necessary. In general, I would say that ignorance is the worst problem I have come across – the inability of sighted people to appreciate the difficulties experienced by people who have (outwardly) no disability.” Male (45 to 64)

EMOTIONAL WELLBEING

Compared with the UK population as a whole, the people living with eye conditions we surveyed reported far more problems achieving a good quality of life (on the day of the survey).⁴⁸ Half (51 percent) felt they couldn’t carry out usual activities (compared with 16 percent of the UK population), and almost as many were in pain or discomfort (48 percent compared with 33 percent) or experienced anxiety and depression (41 percent compared with 21 percent).

⁴⁸ The tool used in the survey is the EQ-5D-3L. © EuroQol Research Foundation. EQ-5D™ is a trade mark of the EuroQol Research Foundation. UK (English) v2.1. Brooks, R., & Group, E. (1996). ‘EuroQol: The current state of play.’ Health Policy, pp37, 53–72.



ASHLEY'S STORY

Ashley, 38 from Hereford, was diagnosed with the rare eye disease keratoconus in 2010, a condition that results in poor vision, and for which there is currently no cure.

He served in the armed forces for 14 years; however, when it was time to renew his contract, his eye condition meant he was no longer fit to serve.

He said: "After I left the army I tried an apprenticeship but it didn't work out because of my eye condition. I had a bit of a meltdown around that time. I was really lost. Retraining and putting so much work into a new job and not being able to do it made me feel hopeless and like I wasn't good enough. At my lowest point, I found myself on the ledge of a third floor window, ready to give up. It was only through the support of my family and the local mental health service that I was able to come back from there."

Ashley has also felt the financial cost of his eye condition.

He said: "After I left the army and the apprenticeship didn't work out I was put on sick pay. Although it meant I had money coming in, it was less than what I was used to which made it difficult financially. There are also a lot of day-to-day costs of having keratoconus, I have no doubt the money I have spent on my condition runs well into the thousands."

Ashley is now a welfare officer for a national charity and does what he can to raise awareness of rare diseases like keratoconus. He said: "When I was diagnosed, there wasn't much support offered to me to prepare me for what was to come. I do my best to raise awareness for my eye condition to help others who are going through the same thing."

Living with pain or discomfort was particularly common for people with multiple conditions. Perhaps more clearly than ever before this highlights just how heavy a burden eye conditions place both on people’s health and emotional wellbeing, affecting all areas of their day-to-day lives.

These findings were backed up by our health economics research carried out by the LSE, whose analysis showed that people living with higher degrees of sight loss report significantly lower quality of life scores. **The quality of life of people with severe sight loss⁴⁹ is lower than of people with a range of other severe physical and mental health conditions, including depression, arthritis and advanced breast cancer.** This should be a major cause for concern.

Responses from 617 individuals indicated that loneliness levels are significantly greater in people with moderate and severe levels of visual impairment. These levels are much higher than would be expected in the general population.

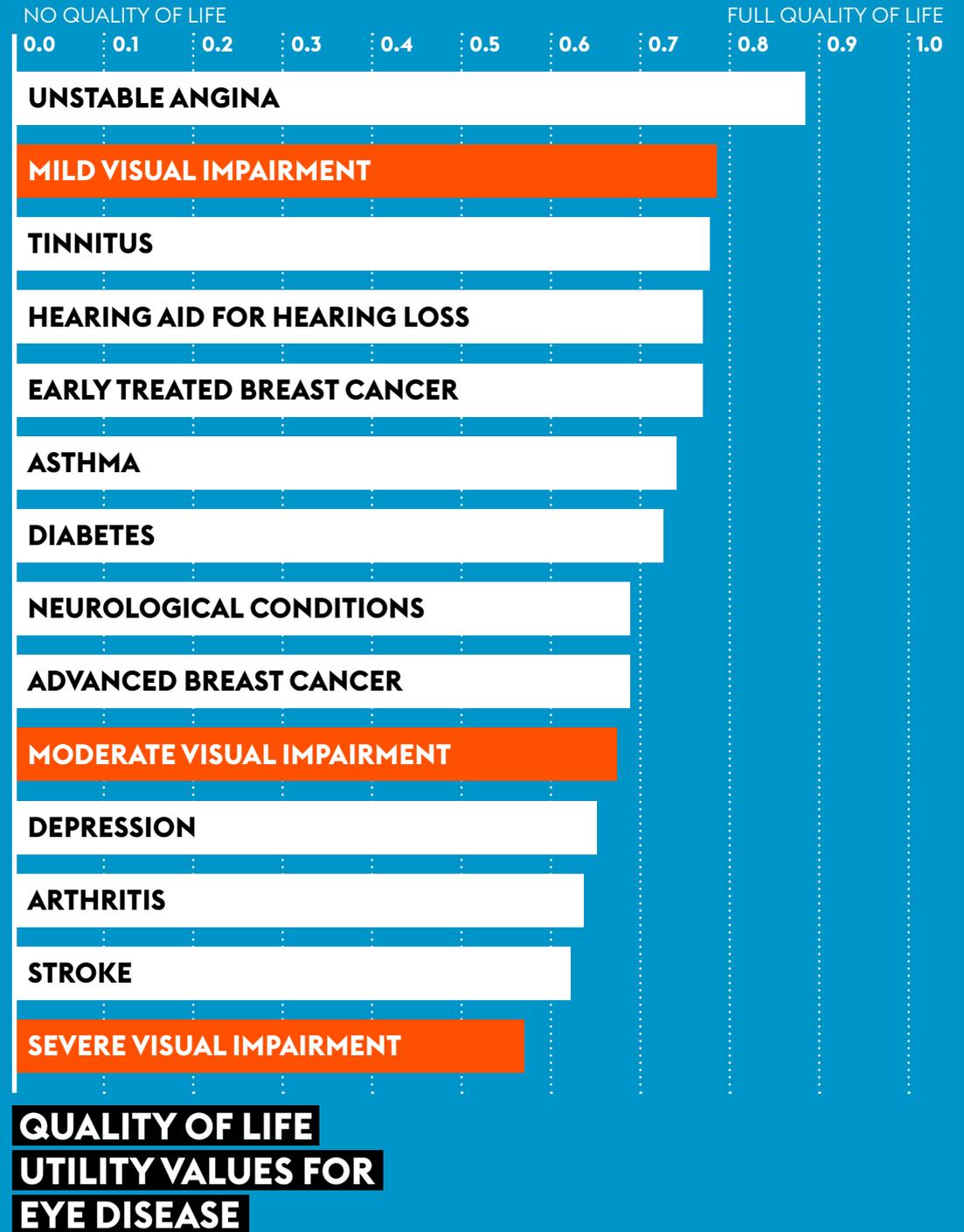
As well as the devastating impact of loneliness on people living with sight loss, this is important as loneliness is associated with poor health outcomes and the need for additional health and social care services.⁵⁰

Both the impacts on quality of life and loneliness were found to be greater in cases where people are living with more than one condition.

While older people are less likely to experience some of the social and financial impacts of sight loss, those aged 65 and over particularly feel their quality of life is affected in relation to pain/discomfort and mobility, likely linked to other age-related health issues.

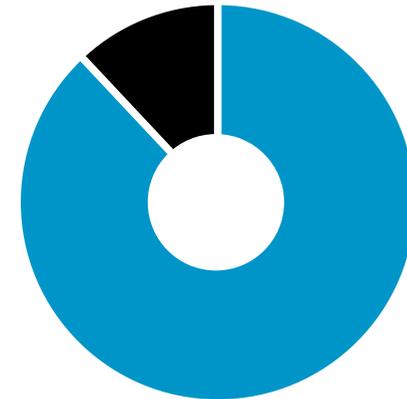
⁴⁹ A score of 0.582, where a value of 1 indicates a year lived in full quality of life and 0 indicates a year with no quality of life.

⁵⁰ Campaign to End Loneliness (no date) Risk to health. Online. Available at: www.campaigntoendloneliness.org/threat-to-health



RECOMMENDATION

Health service commissioners and providers must investigate the benefits of tackling loneliness and poor quality of life – to address the costs to the health and social care sector, as well as the devastating impact on lives.



88%

feel that their condition makes life harder

“My mum had a cataract done a week ago and for the first two days after I had to go in to give her eye drops, three to four times a day. She is very independent, so having to call me for help doesn't come easy for her.”

Daughter of female (over 75)

Almost all (88 percent) of the people we surveyed feel living with their eye conditions makes life harder. And the everyday challenges they face increase with the severity of their conditions.

The biggest impact is on people's mental health and wellbeing, with most (37 percent) finding the **emotional challenges of living with their conditions hardest and many (30 percent) feeling most affected by how their eye condition limits their **independence and freedom** to make choices.**

Seven in 10 people (70 percent) feel some area of their life is limited by their eye condition. This reveals the extent to which sight loss is holding people back from living full lives. The more severe the sight loss, the more likely people are to feel their life has been limited in some way. And women, those under 65 years of age and people who are struggling financially are particularly likely to feel this impact.

Sight loss limits everything from finding and keeping work, education or training (32 percent), to developing personal relationships (21 percent) and being spontaneous (24 percent).

“The biggest thing is the day-to-day, not knowing what’s going to happen next. I may wake up one day – I’ve got a very important meeting at work – and if my eyes are bad, I’m not going. Would I lose my job? You’ve got the added stress. It comes back to health and wellbeing.” Male (under 65)

Over half (52 percent) believe their **leisure and social life** are held back. Again, this impact is felt more strongly by women, those under 65 years of age and people who are struggling financially.

“No relationships as I am never out. I am totally self-dependent with zero friends who visit.” Male (45 to 64)

And almost one in four people (24 percent) think their sight loss has a negative impact on their **personal relationships**.

“I don’t ever want my husband to think that he’s my carer. ...but I do think the balance of us being 50/50 has definitely shifted. I feel less equal in the relationship because of it, which is not nice, obviously.” Female (under 65)

The strain sight loss puts on relationships affects the whole family. Where children and young people have eye conditions, it’s not only their emotional wellbeing that is affected. Their parents or carers naturally also experience increased anxiety and feelings of guilt and helplessness. This increased stress can make working and staying healthy and well more difficult, with knock-on economic impacts as well as personal struggles.

250,000 IN THE UK HAVE CONDITIONS THAT CAUSE SIGHT LOSS & BLINDNESS CHILDREN

Today, almost 250,000 children under 14 in the UK have conditions that cause sight loss and blindness.⁵¹ Our insight shows these younger people with eye conditions are prone to experiencing anxiety and depression. They are likely to feel left out of social circles, leaving them isolated with low self-esteem.

“I feel that she’s quite angry and frustrated a lot of the time. There have been a few things recently ...she was in a terrible mood and really upset and I just couldn’t work out what was wrong. She eventually told me that one of the things she finds so hard is when friends are sharing things on phones ... she says, ‘I can’t join in with that, because I can’t see it!’” Parent of teenager with sight loss

Most of the people with eye conditions we surveyed are worried their conditions will get worse (82 percent) and how they will cope in the future (77 percent).

“The emotional impact is immense. I am terrified about what the future may hold and how much my sight may decline. I am worried that my eye condition will mean I can no longer work. I am scared, confused and feel incredibly low about my condition and wish more support was available.” Female (18 to 44)

⁵¹ Global Burden of Disease Injury Incidence Prevalence Collaborators (2018) ‘Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990-2017: A systematic analysis for the Global Burden of Disease Study 2017’, Lancet, 392 (10,159), pp1,789-858. Available at: ghdx.healthdata.org/gbd-results-tool

RECOMMENDATIONS

Government and policy makers must acknowledge the role of informal carers – to provide them with the necessary financial and respite support.

Government and policy makers must prioritise support for children and young people with sight loss and invest in early diagnosis – to reduce the substantial lifetime economic costs and relieve the stress on families.

“If there was some sort of guarantee that your eyes wouldn’t get any worse, that would be the ideal thing... If I knew that my eyes wouldn’t get any worse for the rest of my life, I could potentially live with that.” [Male \(under 65\)](#)

Many people (59 percent) feel overly dependent on others and most (73 percent) don’t think other people understand what they are going through. This is likely to increase people’s feelings of isolation and loneliness.

“People do not have any idea of what it's like to live with a bilateral, painless, slowly progressive and potentially blinding condition which doesn't make me look any different. I don't think enough attention is paid to mental health issues around the time of diagnosis of a sight-threatening condition.” [Female \(over 75\)](#)

“When I was in a team with people with different disabilities... I got branded as a fraud as I wasn’t blind enough. That hurts. It happens a lot.” [Male \(under 65\)](#)

Half of the respondents (50 percent) feel constrained by not being able to drive due to their sight loss. And many (24 percent) feel less able to use public transport because of their conditions.

“The main thing that affects me really is the fact I can't drive. I live in a little village and we have no train station here. So I don't really get to see my friends in the week. ...I go to work, come back home to do nothing, and then that's it.” [Male \(under 65\)](#)

“It would be much easier for me if I could drive. I would be able to take my children places to ease the pressure from my full-time working husband. The best way I can sum an eye condition up would be to say that it is restricting.”

[Female \(18 to 44\)](#)

When asked to focus on socialising and getting out and about, two thirds of people (67 percent) said their eye conditions put barriers in their way. Not being able to drive was again a common issue (39 percent), followed by a lack of confidence (33 percent) and fear of falling (31 percent).

“The emotional side is hard. I get shy and embarrassed, with minimal eye contact. I am anxious in all new situations and not outgoing.” **Male (18 to 44)**

These emotional and social impacts of eye conditions are felt most by people under 65, especially those with severe or moderate sight loss. Seven in 10 (71 percent) people in this situation feel left out sometimes or often, while a high proportion (73 percent) have low self-esteem and feel isolated (68 percent).

“I feel sometimes that it's harder being visually impaired when you're younger – difficulties socialising at university, difficulties having an active social life (something as simple as going out for the night) – things that aren't primarily due to the eye condition but that are impacted by it.”

Female (18 to 44)

“I miss going out when I want and not having to worry about getting lost or taken advantage of. I miss my friends as some don't bother with me now I'm blind.”

Female (18 to 44)

One in five people with sight loss (20 percent) has a mental health condition, adding to the emotional challenges of living with their eye conditions.

RECOMMENDATION

Government and service providers must consider the impacts of sight loss on young people and working-age adults – to remove barriers and put the necessary services in place to address them.

The mental health impact of sight loss is highest on people with lower incomes, adding to the stress they already face. Of those living with eye conditions with an annual household income under £26,000, over half (55 percent) have low self-esteem, over a third (38 percent) give a weak happiness rating (zero to six out of 10) and one in four (26 percent) has a mental health condition. Almost two-thirds (63 percent) of those who feel their household is struggling financially experience anxiety and depression.

The coronavirus pandemic has had a particularly big impact on the emotional and social life of people living with sight loss.

In our follow up survey, half of working age (18 to 64) people (53 percent) said their eye conditions make it harder to cope with the pandemic. Difficulties include access to food and other essential products (59 percent of those with moderate or severe sight loss), household finances (42 percent of those aged 18 to 64), and work or education (57 percent of those aged 18 to 64).

None of these issues is unique to people living with sight loss, but eye conditions may make it difficult to use the coping mechanisms many of us rely on when isolating, such as video calling, online shopping and mobile banking.

“I have to rely on my husband to help me shop. The times I have gone on my own, no one wants to help with any assistance, even while I use a long cane when shopping. This has made me feel stressed and vulnerable.” [Anonymous](#)

Understandably, the pandemic has made having a social life even more difficult for those with sight loss (85 percent), leading to increased feelings of loneliness (57 percent of those with moderate or severe sight loss).

Social distancing has proved more difficult for people living with sight loss too. Two in five people (40 percent) with severe sight loss find following the guidelines more difficult because of their eye conditions.

“I’m petrified to leave the house as I know I’ll have a full-blown panic attack if I see someone in case I can’t keep to the two metre rule. It’s absolutely frightening and will take me a long time to leave my house and feel safe again.”

[Anonymous](#)

These challenges have added to the already significant impact of sight loss on people’s mental health. Almost half (46 percent) said their mental health is worse because of Covid-19.

HEALTH

Almost all (92 percent) of the people we surveyed have some type of check-up, medication or treatment for their eye conditions. However, most people (70 percent) have an issue with these. A third (33 percent) find them time consuming and almost as many people (30 percent) feel anxious about them or find them expensive (29 percent). Alarmingly, a combined total of more than a quarter reported discomfort (24 percent) or pain (8 percent) related to their treatment.

“The waiting around, and waiting for appointments, and waiting for the results of scans, whether you’re going to need an injection. You’re psyched up for going to the hospital. You get all of the tests, and all of the imaging, and the freezing of the eyes, the dilating drugs, to do all those tests. When you go back another day... they have to do all of those tests all over again. So there’s a duplication I could do without.” [Female \(over 65\)](#)

RECOMMENDATION

Government and policy makers must give retailers and public services guidance and ensure services are accessible – in the shorter term to ensure people with sight loss and blindness can safely social distance and access services during the coronavirus pandemic, and in the longer term to use this moment as a catalyst to ensure people with sight loss can more easily access the services they need.

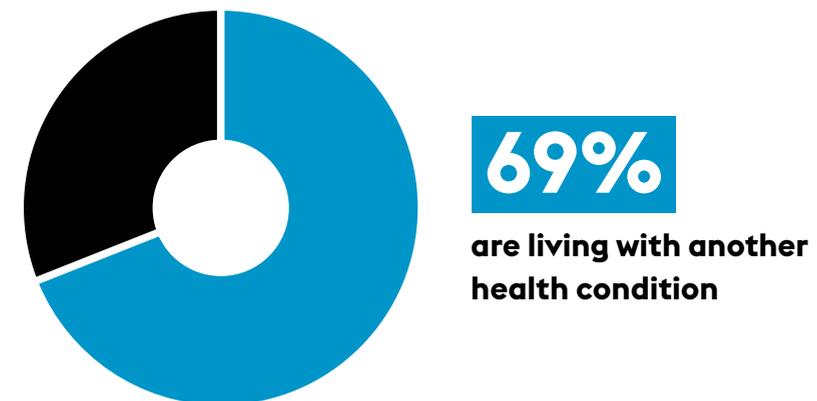
Regarding the type of treatment people receive, most problematic are injections into the eye (90 percent reporting issues). This makes a clear case for research into alternative treatments that are less invasive and more convenient for patients.

“I know there is research ongoing, and I think there are actually clinical trials underway, for drops that would replace the injections. ‘Here are the drops. Put them in tonight before you go to bed.’ And that invasive procedure wouldn’t be necessary, which would be great.” **Female (over 65)**

Eye conditions do not exist in isolation. **Over two thirds (69 percent) of the people we surveyed are living with another health condition.** A third of these (33 percent) have two or more additional health issues.

Older people are much more likely to have one or more other health conditions (78 percent of those aged 65 and over, with 41 percent of this age group having two or more additional health issues). Chronic (long-term) conditions are the most prevalent across the ages.

These findings highlight the importance of treating the person rather than the condition.



DAMIAN, JUSTYNA AND ADAM'S STORY

Damian, 34 from Sutton, and his wife Justyna, were left reeling when their seven-year-old son Adam was diagnosed with the genetic eye condition Stargardt disease, which causes progressive central sight loss.

Damian said: **“Our world fell apart when we got the diagnosis. We were devastated. It was so frustrating to find out that there was nothing that we could do to help Adam.”**

Damian describes how the news that Adam would lose his central vision took a particular toll on Justyna. He said: “Justyna stopped working because she couldn’t cope with the diagnosis. She tried to go into work each day, but she just couldn’t stop crying. Adam is the kindest, most optimistic and energetic little boy. We try our best to be positive for him and not show him that we’re worried, but we are concerned for the future.”

Adam’s diagnosis has also had a financial impact on the family.

Damian said: “We have to make regular trips to appointments and check-ups and we’re constantly buying new glasses as Adam’s prescription changes every few months. We’ve applied for grants for some technology that will support Adam at home and at school, but we don’t know yet if those will come through.”

There is currently no cure for Stargardt disease. However researchers are looking at gene therapy as a possible treatment for the condition. It’s hoped the research can soon be taken to clinical trial and could ultimately lead to a new treatment for the disease.

JOINED UP HEALTHCARE

A holistic approach to health and social care could improve the wellbeing of people living with sight loss, making treatment more affordable, less stressful and more efficient.

The sight loss professionals we interviewed raised the need for better collaboration and sharing between sectors and departments to boost efficiency and cut costs. A lack of data on sight loss was also flagged, which needs to be addressed before information can be better shared.

“You need to take a much broader view about someone’s overall health and lifestyle, because that will be a key driver for what happens to their sight. You need both preventative and treatment-based interventions that will, hopefully, prevent people from experiencing sight loss.”

Sight loss professional

“There needs to be a more joined up, holistic approach to care as well, because, at the moment, it’s all very segregated.”

You see either a stroke doctor, or an eye doctor, or a kidney doctor. Having better linked up healthcare as well as a linked-up approach to prevention and research is going to be key.” **Sight loss professional**

Related to the need for those working on sight loss to be more joined up is the need to improve the transition of research into clinical practice, for example, integrating clinicians into research teams and communicating research to clinicians and trusts. This has potential to increase the value of research even more but requires change in both areas.

“...the training of clinicians is designed to maximise the output of people who can then devote 100 percent of their time to clinical care... And so, trying to maintain opportunities and incentives for people to pursue a harder track of trying to do two things and practise both is not easy.”

Sight loss professional

Our insight uncovered gaps in the support people receive. One in five (21 percent) is not getting the assistance they need (either formally or informally) to go about their daily lives.

Many people are developing their own coping strategies, from using accessible technology and support aids, which add to their outgoings, to limiting their activities, negatively affecting their independence and quality of life.

This highlights how health and social care services are struggling to meet the needs of people living with sight loss.

While curing eye conditions is our ultimate aim, our insight shows the impact that finding and improving treatments can have on people’s lives.

RECOMMENDATION

Health service commissioners and providers must explore the links across different conditions – sight loss and otherwise – and treat patients holistically – to improve the patient experience and save money.

RECOMMENDATIONS

Eye charities must work collaboratively with each other and people with sight loss – to pool resources, increase efficiency and accelerate progress, and ensure our work meets the needs of those we serve.

The sight loss research sector, including funders and industry, must explore more comfortable and less invasive treatments – to reduce the anxiety and discomfort of patients.

Most people (78 percent) feel, if a cure is not possible, a treatment that would halt the progression of their condition or improve it so they need less assistance would make the biggest impact on their quality of life.

This is still the case for people having more invasive treatments for their eye conditions, such as surgery (81 percent) and injections (94 percent). For those with severe sight loss, a treatment that improves their condition so they need less assistance would make the biggest difference to their lives (72 percent).

“What treatments can prevent or delay the onset of your disease? If you think of most diseases in the elderly, if you can delay them by 10 years that’s a massive, massive impact. So it doesn’t all have to be after a cure.”

Sight loss professional

Understandably, two thirds (66 percent) of those who have injections into the eye would prefer treatments that are less painful, less hassle and have fewer side effects.

“I hated it. I absolutely hated it. It’s quite an invasive procedure, and you have to be very, very careful with your hygiene afterwards. There was one month, or two months, where I had injections in both eyes. Well, it was just another devastating week.” **Female (over 65)**

A third of people (34 percent) felt time-saving measures would have the biggest impact on their life, such as treatment being available locally or requiring fewer trips to a hospital.

The coronavirus pandemic has accelerated innovations such as telemedicine and community-based services, which can improve people’s access to the health services they need.

But despite these innovations the coronavirus pandemic has, on the whole, made it even harder for people with sight loss to access the treatment and care they need.

In our follow up survey, almost three in four people (73 percent) said their access to treatment was worse during the pandemic and over half (57 percent) experienced more difficulty accessing care.

Two-thirds (64 percent) of people with eye conditions fear going to hospital for treatment since the Covid-19 outbreak, perhaps contributing to a dramatic fall in the number of people attending appointments for eye care. Many people (39 percent) fear their eyesight will deteriorate due to the reduced access to treatment through the pandemic.

“Waiting times are likely to be much longer as a result of coronavirus, which for me and many others will result in avoidable loss of vision.” Anonymous

A LIFETIME OF SIGHT LOSS

Our insight shows that living with sight loss affects people in different ways at each stage of their life.

UNDER 65

The emotional and social impacts of eye conditions are felt most by **younger people** (under 65), especially those with severe or moderate sight loss. They are prone to experiencing anxiety and depression, and likely to feel left out socially, affecting their self-esteem.

18-65

When people reach **working age**, they are most exposed to the financial impact of their eye conditions. Over a third feel they are struggling financially as a household. And almost two in five of the people of working age with severe sight loss we surveyed are not working due to their eye conditions. This creates a vicious circle of poor emotional wellbeing and a lack of financial security.

OVER 65

Those aged **65 and over** are less likely to experience some of the social and financial impacts of sight loss but more commonly live with other conditions and experience pain and discomfort. Many have trouble going about their day-to-day lives with their eye conditions making other health-related mobility issues even harder to deal with.

RECOMMENDATIONS

Health service commissioners and providers must make services accessible locally or online – to minimise anxiety and disruption for people with sight loss (particularly people over 65). This is especially important during the coronavirus pandemic.

Health service commissioners and providers must focus on preventative therapies and treatments – to prevent sight loss rather than simply manage the impact of eye conditions.

KRISTINE'S STORY

Kristine, 78 from Enfield, first discovered she had glaucoma over 10 years ago. As Kristine's sight loss progressed, she had to rely more heavily on others, which she found difficult.

She said: "I was a very independent person all my life – I travelled abroad quite a lot but now I'm very dependent on my husband and it's taken a lot of time to come to terms with."

Kristine has found getting to and from eye appointments challenging because of her sight loss. She said: "Having driven all my life, to wave goodbye to my car was really difficult. It really limited what I can do."

"I rely on public transport now to get me to my appointments, but I have to go when it's quiet. I learned this because I fell on the platform twice. Now I carry my stick when I don't know somewhere, because at least then people can see I have sight loss and they might need to give me more space."

During the coronavirus lockdown Kristine's check-up appointments were cancelled, leaving her without treatment for several months. She feels her eyesight deteriorated as a result, and she has lost almost all the sight in her left eye now.

In 2014 Kristine was selected to take part in a clinical trial for laser treatment for glaucoma, known as the LiGHT trial (see page 122), which was part-funded by Fight for Sight. She said: "I'm so grateful for the LiGHT trial and eye research because it's paving the way for more insight into glaucoma and how to treat it, which is so important for the future."





THE POSSIBILITIES OF SCIENCE

Solutions

This is an exciting time in eye research, with researchers close to so many breakthroughs that have the potential to transform lives.

New gene therapies are being developed that are already preventing the progression of disease or restoring sight for those with previously incurable diseases. And in some cases these therapies have potential applications beyond the eye, for conditions including cystic fibrosis and even some types of cancer.

The eyes are the window to the body – the only place where blood vessels and nerves are visible externally. Increasing evidence suggests that biometric tests that measure changes in the retina can give early indications of other illnesses, including Alzheimer’s disease, cardiovascular disease and iron deficiency. This paves the way for the eye to be used as a diagnostic for other condition areas.

To date major breakthroughs in eye research, including surgery for cataracts and treatments for glaucoma and wet age-related macular degeneration, have saved the sight of millions of people. And emerging areas like stem cell research, artificial intelligence and gene therapies are making many more sight saving treatments possible. Right now researchers are using stem cells to grow ‘mini retinas’ in the lab, accelerating the process of modelling and developing treatments for disease.

Many people don’t realise the life-changing impact sight loss research can have. But we know it has the power to transform lives.

THE UK'S ROLE IN SIGHT LOSS RESEARCH

Our extensive bibliometric analysis (using statistical methods to analyse research publications) shows the extent to which the UK is a global leader in eye research.

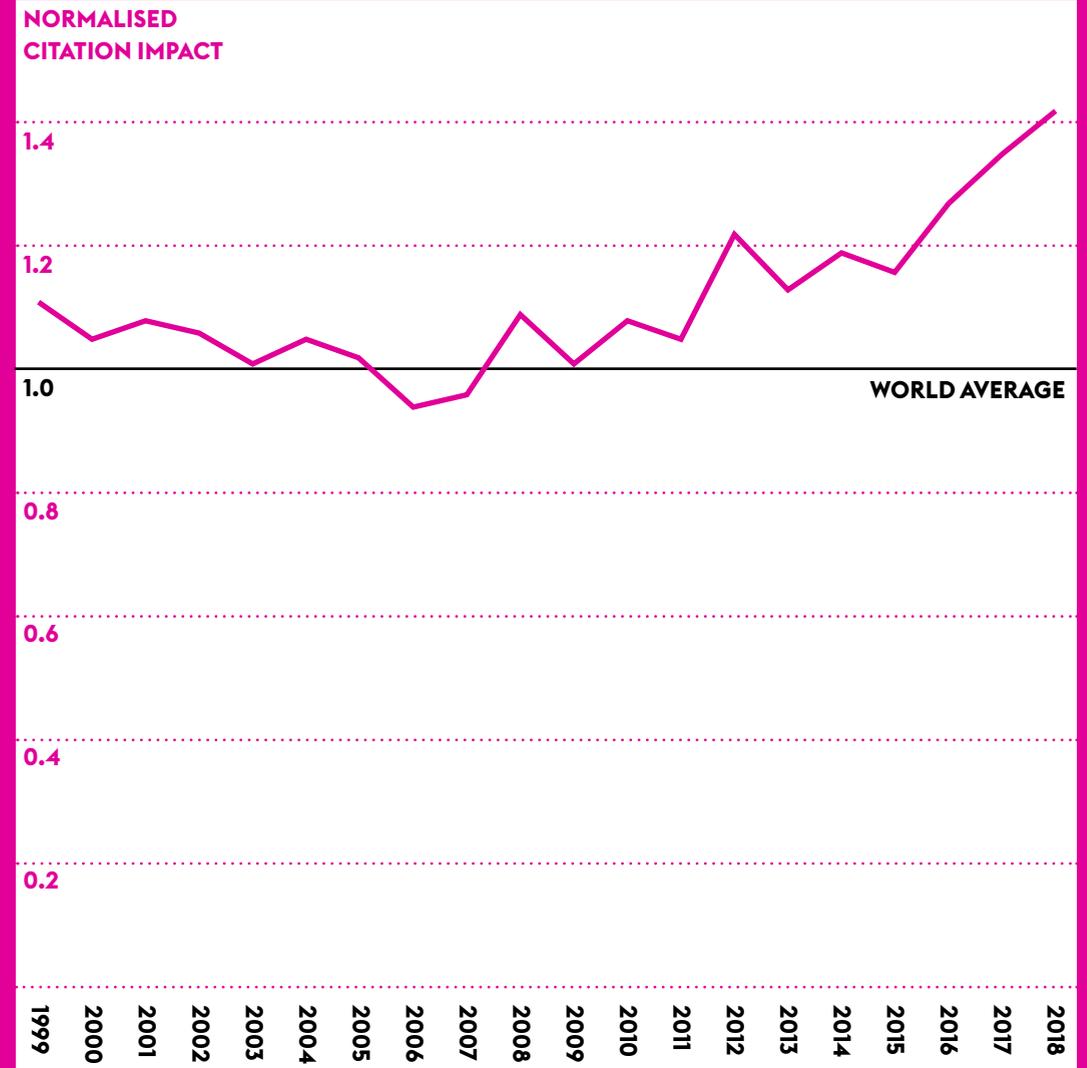
Of more than half a million (548,356) eye research publications published globally between 1999 and 2018, around a tenth (54,281) had at least one UK author. On average the UK's eye research publications receive over 10 percent more citations than the world average. And the percentage of UK publications that are highly cited is substantially higher than the global average.

This shows the influence and impact UK research has on fighting sight loss globally.

Our results also show that the UK is more collaborative when it comes to sight loss research. The eye research publications UK researchers co-author with other countries tend to have a higher average citation impact than for all UK eye research publications.

This highlights that collaborating with sight loss researchers and funding partners across the globe produces research publications with more impact. And it shows the global benefits of investing in sight loss research in the UK. It is vital we can continue to collaborate now the UK has left the European Union.

THE CITATION IMPACT OF UK EYE RESEARCH PUBLICATIONS



RECOMMENDATION

The sight loss research sector, including funders and industry, must continue our national and international collaboration to identify where the need is greatest and focus on research with the biggest potential impact, accelerating progress and transforming more lives.

OUR ROLE IN THE FIGHT FOR SIGHT

Fight for Sight is the UK's leading eye research funder – the only national charity 100 percent focused on funding ground-breaking research into eye conditions that cause sight loss.

Our analysis shows Fight for Sight publications receive 80 percent more citations and are twice as likely to be highly cited than the world average. This is evidence of our expertise in identifying and supporting research with a greater impact than that of other, often bigger, funders.

Fight for Sight funded research has already led to pioneering gene therapies that are beginning to halt or reverse sight loss from inherited eye diseases like choroideremia and Leber congenital amaurosis. And by supporting the recruitment, retention and career development of talent, we've contributed to keeping the UK at the forefront of ophthalmology research.

We are now supporting the brightest minds in vision research to use the latest technologies and approaches, including artificial intelligence, to diagnose conditions at an earlier stage.

And our research projects into glaucoma, age-related macular degeneration and diabetic retinopathy are taking us towards our target of new treatments for the leading causes of blindness in the next decade. We fund hundreds of researchers who are so close to exciting breakthroughs.

The challenge is the sheer number of different eye conditions that we need to tackle. That's why we're investing nearly seven million pounds in 117 projects at leading universities and hospitals across the UK, to transform lives all over the world.

This significant investment is thanks to our supporters and partners, who see the vital role research must play in our mission to end sight loss. They invest in us because they understand the value Fight for Sight has to offer.

We play a vital role in funding early stage research that will lead to the next breakthrough and treatments to help people with sight loss. Here are some of our successes.

FIGHT FOR SIGHT FUNDED RESEARCH SUCCESS

Through the Tommy Salisbury Choroideremia Fund, vital early stage research at Imperial College in 2008 led to the development of a new gene therapy treatment for choroideremia.

The treatment halted the disease and even restored sight for some patients in a clinical trial led by Professor Robert MacLaren at Oxford University. When approved, the treatment (currently in phase III clinical trials) will be the world's first gene therapy for this condition. The same team is now investigating whether this technology can transform the lives of people living with Stargardt disease and other inherited retinal diseases. (See pages 112 and 114.)



Professor Robert
MacLaren

AVERAGE CITATION IMPACT OF EYE RESEARCH FUNDERS

RESEARCH TO PREVENT BLINDNESS

1.40

NIH NATIONAL EYE INSTITUTE (NEI)

1.44

GERMAN RESEARCH FOUNDATION (DFG)

1.40

MEDICAL RESEARCH COUNCIL UK

1.72

EUROPEAN UNION (EU)

1.43

WELLCOME TRUST

1.67

FIGHT FOR SIGHT

1.81

WORLD FIRST GENE THERAPY FOR CHOROIDEREMIA



In 2008 Fight for Sight funds Professor Seabra at Imperial College London, thanks to funding from the Tommy Salisbury Choroideremia Fund



His research is published in Investigative Ophthalmology & Visual Science in 2009, establishing which gene is responsible for choroideremia



Initial findings are published in Investigative Ophthalmology & Visual Science in 2010 and cited 51 times



Further research builds on this breakthrough, led by Professor MacLaren's team at University of Oxford



Dr Kapetenovic from the Oxford team



A patent for gene therapy is created in February 2011



A clinical trial for a choroideremia gene therapy follows, with results published in the Lancet in 2014 and cited 369 times



Joe experiences improvements in his vision after taking part in the clinical trial in 2015

FIGHT FOR SIGHT FUNDED RESEARCH SUCCESS

Earlier this year, Dr Colin Chu and his team at the University of Bristol designed a new gene therapy for glaucoma in the laboratory.



The researchers have used a gene-editing technique called CRISPR to alter the genetic information in the eyes with a single injection. They've found that by switching off a gene called aquaporin 1 they can prevent the build-up of fluid and stop the increase in eye pressure that damages the optic nerve. The researchers are planning to take the treatment to a clinical trial, potentially revolutionising glaucoma treatment in the next decade.

FIGHT FOR SIGHT FUNDED RESEARCH SUCCESS

Professor Mike Cheetham at the UCL Institute of Ophthalmology has worked with scientists from ProQR Therapeutics in The Netherlands to pioneer a new genetic technique for treating a type of Leber congenital amaurosis.



Professor Mike Cheetham

The condition is the most common form of childhood inherited blindness and affects two or three in every 100,000 newborn babies, eventually leading to blindness. Until now there has been no treatment. In clinical trial results announced in 2019, Professor Cheetham's technique successfully restored some sight in 10 people, with one patient able to see lights with increasing clarity and brightness for the first time in decades.

JOE'S STORY

Joe, 28, is a teacher from Croydon who was diagnosed with the degenerative eye disease choroideremia at the age of 10.

Throughout his teenage years as his condition worsened and his sight started to deteriorate, Joe struggled mentally and emotionally, and began to withdraw socially. When training to be a teacher he heard about clinical trials into his condition, and in 2015 he decided to put himself forward. He had the treatment under general anaesthetic and later went back to hospital for an eye test.

He said: "I told Dad I'd read all four lines. My dad – a real man's man – broke down and we both just held each other crying. All I felt was relief and happiness. I'd never have 20/20 vision, but I would not go blind."

Joe said: "Thanks to the research funding of Fight for Sight I no longer have to prepare for going blind due to ground-breaking gene therapy which has stopped me losing my sight and even brought some back."

Through the Tommy Salisbury Choroideremia Fund, we provided funding for the initial research that led to a world-first clinical trial for choroideremia by Professor Robert MacLaren at the University of Oxford.

As a result of this successful trial, a new company called NightstaRx therapeutics was formed as a spin-out from the university. NightstaRx has developed a gene therapy called NSR-REP1 and the company has announced the initiation of the phase 3 trial for the choroideremia treatment.



THE FIGHT AHEAD – AND CASE FOR INVESTMENT IN EYE RESEARCH

We face an enormous challenge to transform the lives of 2.5 million people with hundreds of eye conditions in the UK alone. And it's a challenge that will only get bigger with our ageing population.

Covid-19 has made this fight even harder – with our survey of researchers showing that over 90 percent predict delays to their research and long-term uncertainty over funding. This evidence has been further supplemented by research from the Royal College of Ophthalmologists showing the widespread impacts of the pandemic on ophthalmology research.⁵²

Yet investment in eye research is now more important than ever and must not be deprioritised. With sight loss having such a profound impact on millions of people in the UK it makes sense to invest in solutions that will transform lives and take pressure off an already stretched NHS and wider economy.

The need is there. The science is there.

The talent is there.

The funding is not.

⁵² Royal College of Ophthalmologists (2020) Mitigating the impact of Covid-19 on academic ophthalmology and ophthalmic research. RCOphth. Available at: www.rcophth.ac.uk/wp-content/uploads/2020/07/Covid-19-and-Academic-Ophthalmology-and-Ophthalmic-Research-July-2020.pdf

GENETIC TECHNIQUE FOR LEBER CONGENITAL AMAUROSIS TYPE 10



In 2014, Fight for Sight funds Professor Mike Cheetham at UCL to investigate whether antisense oligonucleotides are effective in tackling LCA in 'mini retinas' grown in the lab

In 2016 a proof of concept study shows that antisense oligonucleotides are effective in mini-retinas, with results published in Cell Stem Cell journal

The results, which are published in Molecular Therapy Nucleic Acids, help gain authorisation for a clinical trial in humans which begins in 2017

Professor Cheetham goes on to work with ProQR in the Netherlands to test their RNA genetic therapy as a treatment for LCA



This small clinical trial follows with results published in Nature Medicine in December 2018, showing that the therapy has improved the sight of patients within three months



With more research this breakthrough offers hope of new treatments for Jackson and others living with different types of LCA



RECOMMENDATIONS

The sight loss research sector, including funders and industry, must invest in the latest technologies and techniques, and continue to support research infrastructure and careers – to harness the potential of new approaches, and ensure ophthalmology research retains the best and brightest talent in the world.

Eye charities must substantially increase investment in eye research; three percent of income is not enough – to shift the balance from focusing purely on care and support for people with sight loss.

FIGHT FOR SIGHT FUNDED RESEARCH IN PROGRESS

Professor Alan Stitt, Dr Reinhold Medina and Dr Imre Lengyel at Queen's University Belfast are studying the role of damage to tiny blood vessels at the back of the eye in dry age-related macular degeneration.



Professor
Alan Stitt

There is currently no treatment for 90 percent of cases of this leading cause of blindness. The team is exploring the potential of drugs that can boost the capacity of blood vessels to repair themselves as a way of treating the condition. This pioneering research could prevent the disease from progressing to later stages, saving people's sight and changing their lives.

Our insight makes clearer than ever the high quality of the UK's sight loss research, and the valuable contribution of Fight for Sight in particular. We have made a life-changing impact with a fraction of the investment needed in eye research.

Imagine what we could achieve if sight loss were given the resources and funding it needs.

Our new costing model shows the enormous economic impact of reducing the prevalence of eye conditions in the UK.

Estimates from our costing model show that if we reduce the prevalence of eye conditions by just one percent each year we could make a cumulative saving to the UK economy of up to £3 billion over the next decade and £9.5 billion by 2050. This would save NHS and social care services a potential £1.5 billion

ONE PERCENT reduction in
prevalence each year for a **DECADE**

£3 BILLION **SAVED**

£9.5 **ONE PERCENT** reduction in
prevalence each year until **2050**

BILLION **SAVED**

- Our study has shown the largest costs are associated with age-related macular degeneration, for which there is currently no treatment in 90 percent of cases. Reducing age-related macular degeneration prevalence by just one percent each year could save the UK economy nearly £1.2 billion by 2050.
- Reducing glaucoma prevalence by one percent each year could save the UK economy over £325 million by 2050
- Reducing type 2 diabetes-related diabetic retinopathy prevalence by one percent each year could save the UK economy over £150 million by 2050

THE EVIDENCE RESEARCH CAN MAKE A DIFFERENCE

Investing in research to tackle these leading causes of sight loss has the potential to deliver a significant return on investment for the UK economy, relieve the strain on the NHS and social care services and, most importantly, transform hundreds of thousands of lives around the world.

For example, in a series of studies into the economic returns on research investments into cardiovascular, mental health, cancer and musculoskeletal diseases, researchers estimated that every pound spent on medical research would generate a 25 pence return in improved health and wider benefits to the economy. The authors concluded that it was not unreasonable for the estimates to apply to any health-related public research.⁵³

In addition, research into cataracts has led to surgical procedures that have transformed millions of lives globally and saved billions of pounds.⁵⁴ Cataract surgery improves the quality of life of hundreds of thousands of people in the UK every year, as well as having economic benefits to society.

⁵³ Grant J, and Buxton MJ (2018) 'Economic returns to medical research funding', BMJ Open, published online: 20 September 2018. Available at: bmjopen.bmj.com/content/8/9/e022131.info

⁵⁴ ScienceDaily (2013) Cataract surgery saves \$123.4 billion in costs, delivers 4,567 percent return to society. Online. Available at: www.sciencedaily.com/releases/2013/11/131115104553.htm

FIGHT FOR SIGHT FUNDED RESEARCH IN PROGRESS

A project at the University of Cambridge, led by Professor Keith Martin, aims to repair the damage caused by glaucoma by strengthening the connection between the eye and the brain through protecting and regenerating nerve cells.

Currently once sight has been lost due to glaucoma there is no way of restoring it, so finding a way to repair the optic nerve would revolutionise treatment in this area.



Professor Keith Martin

FIGHT FOR SIGHT FUNDED RESEARCH IN PROGRESS

Professor Majlinda Lako and her team at Newcastle University are using the latest pioneering stem cell techniques to develop a model for treating children with an eye cancer called retinoblastoma.



Professor
Majlinda Lako

The researchers will use stem cells taken from blood samples of patients with retinoblastoma to gain more information about which retinal cells are affected. They believe their findings will help to identify patients whose sight could be saved as well as increasing the success of eye injections during chemotherapy so that the therapy reaches every affected cell, increasing the chances of saving children's sight.

The LiGHT trial (Laser in Glaucoma and Ocular Hypertension Trial), part-funded by Fight for Sight, comparing the effectiveness of laser-based treatment for newly diagnosed cases of glaucoma with the current method of using intraocular pressure-lowering eye drops saw less need for treatment to be escalated and a reduced need for both glaucoma surgery and cataract extractions. The new treatment could potentially save the NHS and social care services up to £1.5 million a year in direct treatment costs for newly diagnosed patients.

To make the scientific breakthroughs that make diagnosing, treating and reversing sight loss possible, a significant increase in eye research funding is needed now. This must be supported by awareness campaigns and promotion of lifestyle changes to prevent avoidable sight loss.

RECOMMENDATION

The sight loss research sector, including funders and industry, must commit more investment and collaborate more, to diagnose early, stop progression of disease and restore sight. They should also support more epidemiological research to generate accurate data and identify areas of greatest need. Industry partners can then play a leading role to scale up translation towards transformative treatments.

RECOMMENDATION

Government and funding bodies must double public investment in sight loss research from £24 million (1.5 percent of public grant funding for medical research) to at least £50 million by 2030 – and use our flexible costing model to plan for the future.

While doubling investment in eye research would still only take us part of the way, increased investment would transform hundreds of thousands of lives, save the economy money, and keep the UK at the forefront of ophthalmology research.

Increased investment of this scale is possible when the government takes a health condition seriously. Between 2012 and 2015 the UK government doubled investment into dementia medical research and in 2017/18 they invested the equivalent of £97 for every person with dementia.⁵⁵ In contrast just £9.60 is currently invested in eye research for each person with sight loss.

Our study shows that a focus on investment in new treatments for high-cost and high-prevalence conditions like age-related macular degeneration and diabetic retinopathy – which are currently untreatable in many cases – could have the biggest impact.

⁵⁵ www.dementiastatistics.org

With at least 2.2 billion people living with sight loss or blindness globally, we need a joined-up approach with a single focus that meets the scale of the challenge we face – a challenge that is bigger than ever due to the impact of Covid-19.

This report demonstrates the potential of science, which we know is so close to breakthroughs, if only the investment could be put in place. We have shown it makes sense from an economic perspective. And, more importantly, we have shown it makes sense from a human perspective.

Working together to tackle this public health crisis, we can radically reshape the future for everyone affected by sight loss.

It's time to focus.

All of the original research findings can be found in the appendices, available to download at www.fightforsight.org.uk



TIME TO FOCUS

GET IN TOUCH

For more information on this report,
or the work of Fight for Sight,
visit our website:

www.fightforsight.org.uk

Email:
info@fightforsight.org.uk

Phone:
020 7264 3900

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