

# **IN SIGHT: A REVIEW OF THE VISUAL IMPAIRMENT SECTOR**

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## EXECUTIVE SUMMARY

**Almost two million people in the UK are living with some degree of sight loss.** Yet more than half of this loss could be avoided—by wearing correctly-prescribed glasses, or accessing the right treatment at the right time.

Visual impairment is a growing problem: the number of people with sight loss is expected to double by 2050 as the population ages and underlying causes like diabetes and obesity increase. Eye care services are stretched, and the NHS faces a perfect storm of growing need and squeezed budgets. But the visual impairment sector is rising to the challenge, and uniting in a way not seen before to push for positive change.

This promising trend of collaboration amongst visual impairment organisations could help the sector work together to identify, treat and prevent sight loss, and deliver the joined-up care that is badly needed. VISION 2020 (UK) Ltd's *Adult UK sight loss pathway* sets out the journey across health and social care to enable smooth transition between services. Initiatives like this can help the sector become more influential, improve patients' experiences, and put eye health on the government agenda. Results are already being seen: in April 2013 a national eye health indicator was added into the government's new Public Health Outcomes Framework, a first for the sector.

The public is not well-informed about the importance of eye health and the hereditary nature of some eye diseases, and the voluntary sector has a key role to play in raising awareness. A 2012 survey found 29% of UK adults had not heard of age-related macular degeneration (AMD), the most common cause of blindness in the UK. Sight loss could be avoided by timely treatment of conditions such as glaucoma, diabetic retinopathy and certain types of AMD, which can be dealt with most effectively if diagnosed early. Investment in healthcare infrastructure is also needed: at present, half of all hospitals cannot treat AMD in the recommended time—yet left too late, damage from AMD is irreversible.

Now is a pivotal time for visual impairment: the growing need provides the impetus for the sector and government to develop better ways of working, and to invest in medical research. Charities can give people affected by sight loss a voice in the debate, and speak up for their interests.

### Older people and visual impairment

In the UK, one in five people over 75, and one in two people over 90, is living with sight loss. Older people with significant visual impairment can face a bleak future of shrinking horizons—but it doesn't need to be this way. Sight loss could be avoided in many cases by increased awareness, early diagnosis and effective treatment.

- **Older people wait too long to engage with eye care**, and many see sight loss as a natural part of ageing. 50-70% of sight loss in older people is treatable, but less than half of over-60s have an annual sight test. People can be put off visiting a high street optician by worries about having to buy expensive glasses.
- **Visual impairment may not be adequately understood by professionals.** Many older people have regular contact with healthcare professionals, but if eye health is not a priority, problems go un-recognised. Specialist rehabilitation workers to help people adjust to sight loss are in short supply.
- **The support needed to adjust to visual impairment is insufficient.** It is much easier to stay independent as sight deteriorates if coping techniques are learnt early on. Support to avoid isolation (physical and social), deal with the emotional impact of visual impairment, and make practical adaptations to routines and surroundings, is often provided by Eye Clinic Liaison Officers (ECLOs). But at present provision is patchy.

#### What can make a difference?

- **Investing in early intervention services**—for example, a strong public health campaign to challenge the assumption that sight loss is a natural part of ageing, and emphasise good eye health, could help avoid some

sight loss. Practical changes, for example bringing optometrists into GP surgeries, could make it easier for older people to access eye tests. More ECLOs would mean more ongoing support for people to maintain independence and ensure they register for council support. Investing in reablement—building skills to adapt to an independent life with a visual impairment—can decrease reliance on social care.

- **Developing joined-up working across the charity and public sectors** could help integrate visual impairment with wider health services and charities working with older people, to increase understanding of its importance to overall care. There are already some excellent initiatives in this area, and charities have the convening power to expand these pockets of cross-sector working even further. Campaigning for policy change to get visual impairment onto healthcare agendas for all older people should be a priority.

## Medical research

People with sight loss want to be able to play a full role in society, but also want their lost sight back. This will only become possible with advances in medical research into sight loss, which many feel is underfunded and overlooked. But recent developments, such as the choice of eye health as one of the clinical priorities for GPs over the next three years, and the national eye health indicator, are positive: visual impairment organisations are working together to push the medical research agenda, and we know what patients and professionals want research to focus on. The case for investment in medical research is strong.

- **The sector is at a pivotal point**, with collaboration increasing. Thanks to cross-sector consultation—notably the recent Priority Setting Partnership (PSP)—we know what patients and professionals consider the priorities for research. The sector is perfectly positioned to move forward.
- **Medical knowledge is advancing rapidly, but has a way to go.** Eye research has seen notable recent successes, but much more research is needed: many different eye diseases have unknown causes or no treatment. Where there is treatment it may not work for everyone, and often cannot reverse sight loss.
- **Eye research is underfunded.** The sector receives £30m annually for eye research—about £83 per year for each person registered as visually impaired. This is low compared to other diseases.
- **Eye research infrastructure is not prioritised**, and needs improving.

### What can make a difference?

- **Developing a strong sector profile and united voice to support medical research:** cross-sector support is growing, and we need to ensure we capitalise on this trend to go further to raise the profile of eye disease, for example, with an awareness campaign about medical research. The refreshed *UK Vision Strategy* refers to medical research for the first time, which is a step in the right direction, but not enough.
- **Ensuring maximum impact by carrying out the right research in the right way.** Increasing the resources in crucial areas of the research chain, such as translational research, helps avoid the ‘valley of death’ between basic discoveries and drugs ready to be tested on humans. New business models for research, such as private funding and corporate partnerships, can also move the process along. Asking people affected by visual impairment what matters to them, through public-patient involvement, identifies the ‘right’ research.
- **Structuring medical research to achieve maximum impact**—investing in the whole eye research sector in the UK to enable excellence. For example, bolstering the research workforce through investment in the next generation of scientists and retaining experts in eye research; developing a more connected research network and linking professionals closer together; building collaboration and alliances with commercial companies with an interest in eye health; developing an eye research data repository to provide reliable data in the sector; and establishing a government clinical lead for eye health.

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# INTRODUCTION

## About this report

*'We were interested in funding a piece of research which, as well as being of direct relevance to the foundation, might be of use to other grant-makers, and to organisations in the UK.'*

*Since visual impairment has long been a focus area for the foundation via the Clothworkers' Charity for Welfare of the Blind and, since there seemed to us to be little in the way of recent reports or publications in this area, we asked NPC to undertake this research project for us.*

*We are delighted to be supporting the research which we hope will be of value to grant-makers, charities and others working in the area of blindness and visual impairment.'*

**Philip Howard, Grants Manager, The Clothworkers' Foundation**

Loss of sight is the disability we fear most: 76% of us would rather lose a limb than our eyesight.<sup>1</sup> Yet often we seem to accept the gradual deterioration of our sight, adapting to it, and not seeking help and advice in time.

As our eyesight deteriorates our horizons can shrink and we can gradually become more isolated and lonely. Almost half of blind and partially sighted people feel 'moderately' or 'completely' cut off from people and things around them.<sup>2</sup> People with sight loss are more likely to experience depression; older people with sight loss are twice as likely to experience depression as their peers with good vision.<sup>3</sup> People with sight loss are also more likely to be unemployed and poor.<sup>4</sup>

The number of people that will experience some form of sight loss is set to double between now and 2050. Many doubt the capacity of the healthcare system to manage this surge in demand. Yet there does not seem to be any sense of crisis or urgency. Why is this?

This report can only scratch the surface of what is a huge and complex sector, and one that overlaps with many others. For this reason we have tried to focus on possible gaps in knowledge, or areas that would benefit from debate. We do not seek to add to already well-documented areas and make no apology for steering away from any broad discussion of the wider changes in the health system, which is outside the scope of this report.

This report is the result of three separate pieces of work, which began with a scoping phase to identify the main issues faced by the sector and by those with sight loss. From the list of major themes that emerged from the

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1 Bausch and Lomb (2012) *The Global Eye Health Barometer*. Bausch and Lomb.

2 RNIB website. *Key information and statistics*. Accessed October 2013.

3 Evans, Fletcher and Wormald (2007) *Depression and anxiety in visually impaired older people*. *Ophthalmology*, Volume 114 (2), p. 283–288. American Academy of Ophthalmology.

4 Gjonca E and Nazroo J (2005) *An investigation of the circumstances of older people with sight loss: Analysis of the English Longitudinal Study of Ageing*. Thomas Pocklington Trust.

scoping phase two topics were selected to research in more detail: issues surrounding visual impairment for older people; and the funding and current state of eye medical research.

All the issues identified in the scoping phase merit further research, and our selection of these two is by no means intended to suggest that some are more worthy of research than others.

The report is divided into two sections:

- A broad **overview of the visual impairment sector**, which provides context for the more detailed research. This section looks at the number of people that currently suffer from sight loss, and its main causes. It describes the care pathways and provision currently in place to treat and care for people with sight loss.
- A section covering each of the two focus areas:
  - **Older people with visual impairment** face particular issues, and are the subject of the first area. A major concern is access to support, including the need for accurate diagnosis, availability of eye care, and the suitability of mainstream older people's services to deal with visual impairment. A second concern is the difficulty of adapting emotionally and practically to sight loss. This report explains the work charities are doing in this area, discusses approaches that could make a difference and makes recommendations for funding.
  - The **funding of medical research** is the second focus area. This report provides some background to the medical research sector and estimates the level of funding that eyes receive. It looks at the structure of the sector and considers developments that have already taken place. This section goes on to address what could be done differently to improve the sector, and explores opportunities for funders in this area.

## The purpose of this report

This report aims to do several things:

- highlight and explain potentially under-researched and underfunded issues in visual impairment;
- add to the debate surrounding visual impairment and draw out key themes;
- identify what works to tackle problems; and
- identify gaps in funding and opportunities for funders.

## Who this report is for

- Funders interested in the visual impairment sector, including trusts and foundations, individual philanthropists, government funders and institutional funders of medical research.
- Charities that work within the visual impairment sector to provide advice and services.
- The general public, in particular potential beneficiaries and those who care for them.
- Policymakers within national and local government.

# VISUAL IMPAIRMENT: AN OVERVIEW

The growing number of people with sight loss is putting pressure on healthcare systems, resulting in larger waiting lists and longer periods between appointments. At the same time, cuts in social service provision have raised the bar in terms of eligibility, leaving many people with sight loss unable to access the services they need. The consequences of delayed and restricted care for individuals with sight loss are serious: well-being suffers as sight deteriorates, horizons shrink and loneliness grows.

Despite the increasing prevalence of sight loss, the general public is not well-informed. Many people do not know that they are more susceptible to some eye diseases, and eye health is not taken seriously. But there are signs that the concerns of the eye sector are gaining traction—probably because of the massive budgetary implications for healthcare, but also due to increased collaboration by the sector itself.

## What is visual impairment?

Visual impairment is when a person has sight loss that cannot be corrected using glasses or contact lenses. This can be the result of degenerative conditions, congenital conditions, trauma or disease.

The *Future Sight Loss UK*<sup>5</sup> definition is shown in Box 1 below.

### Box 1: Defining visual impairment

Partial sight and blindness can be broadly defined as a limitation in one or more functions of the eye or visual system, most commonly impairment of visual acuity (sharpness or clarity of vision), visual fields (the ability to detect objects to either side or above or below the direction in which the person is looking), contrast sensitivity and colour vision.<sup>6</sup>

There are two main areas that are examined when someone's vision is measured.

- **Visual acuity**, which is your central vision and is used to look at objects in detail, for example when reading a book or watching television. Visual acuity is measured by an ophthalmologist by reading down an eye chart.
- **Visual field**, which is your ability to see around the edge of your vision whilst looking straight ahead. This is measured using a field of vision test.

Quantifying visual impairment in the UK throws up two issues for discussion. First, official figures underestimate the scale of the problem, as they are based on the number of people registered with their local authority. And second, the number of people with sight loss is increasing, partly due to the UK's ageing population. Both these issues are explored in more detail below.

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<sup>5</sup> Access Economics (2009) *Future sight loss UK (1): the economic impact of partial sight and blindness in the UK adult population*. RNIB and Access Economics.

<sup>6</sup> Access Economics (2009) *Future sight loss UK (1): the economic impact of partial sight and blindness in the UK adult population*. RNIB and Access Economics.



## Registration understates the number of people with sight loss

If the results of a vision examination show that a person is blind or partially sighted, an ophthalmologist will issue a Certificate of Vision Impairment (CVI).<sup>9</sup> The combination of the test of visual acuity and visual field is considered when deciding if a person is eligible for a CVI.

### Box 2: Categories of visual impairment used for certification and registration purposes

There are two main categories of visual impairment\*.<sup>7</sup>

- partially sighted or sight impaired, where the level of sight loss is moderate; and
- severe sight impairment (blind), where the level of sight loss is so severe that activities that rely on eyesight become impossible.

\* This is an administrative as opposed to clinical definition. Clinical definitions use measures of visual acuity.<sup>8</sup>

Practices around certification vary, and a number of barriers to certification have been identified. These include: uncertainty of ophthalmologists around when to certify; external pressure not to certify patients; consultants delaying certification until all medical options have been undertaken; and poor awareness by health professionals of the benefits of being certified and registered.<sup>10</sup>

A CVI enables a person to register with local social services, which can entitle them to a number of concessions and make it easier to claim benefits (Box 3).

### Box 3: Benefits of registering as sight impaired or severely sight impaired<sup>11</sup>

Blind person's personal income tax allowance (worth £2,160)

Free NHS sight tests

Protection under the Equality Act (Disability Discrimination Act in Northern Ireland)

A range of benefits and concessions including a reduced television license fee, free postage for items for the blind, a disabled person's railcard, blue badge and help with telephone charges and line rental

Locally determined benefits such as travel schemes and concessions for leisure activities

<sup>7</sup> NHS Choices website. *Visual impairment overview*. Accessed October 2013.

<sup>8</sup> Partial sight, or sight impairment, is usually defined as: having very poor visual acuity (3/60 to 6/60) but having a full field of vision; or having a combination of moderate visual acuity (up to 6/24) and a reduced field of vision or having blurriness or cloudiness in your central vision; or having relatively good visual acuity (up to 6/18) but a lot of your field of vision is missing. The legal definition of severe sight impairment (blindness) is when 'a person is so blind that they cannot do any work for which eyesight is essential'. This usually falls into one of three categories: having extremely poor visual acuity (less than 3/60) but having a full field of vision; having poor visual acuity (between 3/60 and 6/60) and a severe reduction in your field of vision; and having average visual acuity (6/60 or better) and an extremely reduced field of vision. NHS Choices website.

<sup>9</sup> In Scotland, this is a BP1 form.

<sup>10</sup> Boyce T (2012) *The certification and registration processes: stages, barriers and delays*. RNIB.

<sup>11</sup> RNIB website. *Registration – the benefits*. Accessed October 2013.

Every year, 23,000 people lose their sight and register as either blind or partially sighted. Registration is voluntary, and it is widely thought that the number of registrations understates the actual number of people who are blind or partially sighted, therefore many do not access all the benefits that they are entitled to. Research by the Royal National Institute of Blind People (RNIB) has found that the number of new registrations is falling despite the prevalence of sight loss increasing.<sup>12</sup>

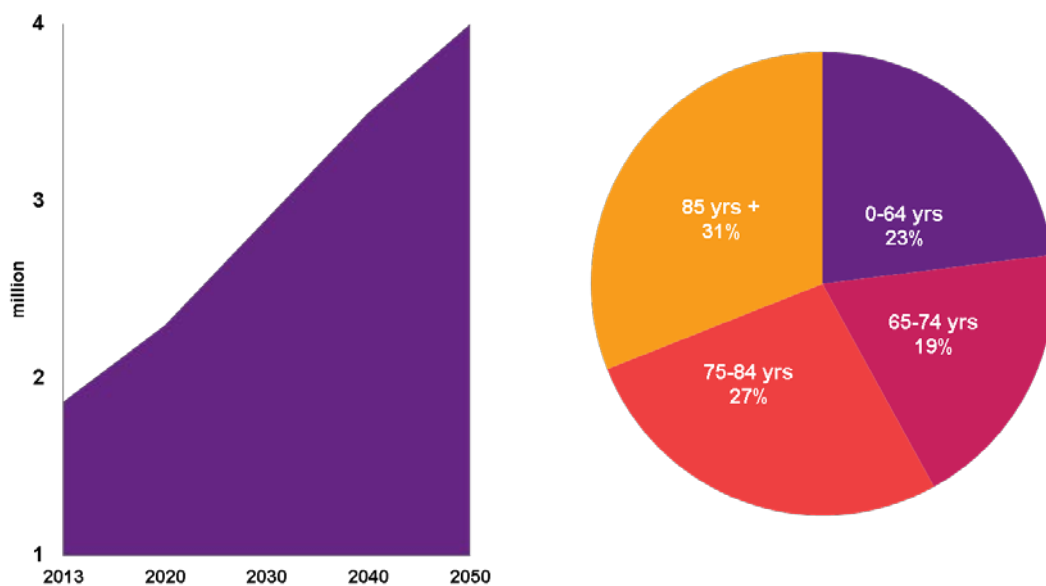
## The number of people with sight loss is increasing

Around two million people in the UK are living with some degree of sight loss.<sup>13</sup> This number is expected to double by 2050 as the UK population ages. Included in this figure are: 360,000 people registered as blind or partially sighted in the UK;<sup>14</sup> those that are waiting for treatment; those whose sight could be improved; those that have not registered for whatever reason; and those whose sight loss is not at a level that allows them to register.

Sight loss affects people of all ages, but the prevalence of sight loss increases with age.<sup>15</sup> One in five people aged 75 years and over are living with sight loss. There is also growing incidence of key underlying causes of sight loss such as obesity and diabetes.

Figure 1 shows the projected increase in the number of people living with sight loss. The increased prevalence is a modelled estimate and is entirely based on changes in demography. Figure 2 shows the breakdown of people living with sight loss by age.<sup>16</sup>

Figure 1: Projected increase of people living with sight loss. Figure 2: Age of people living with sight loss.



Source: RNIB (2013) *Sight Loss UK 2013*. RNIB.

Over 50% of the sight loss among the two million people mentioned above can be avoided. This figure is based on the number of people whose sight could be improved by wearing correctly-prescribed glasses, or having the right treatment at the right time. It takes into account sight loss that could be avoided by timely treatment of

12 Kaye, A. and Connolly, P. (2013) *Facing blindness alone: What government needs to do now to stop the isolation of blind people*. RNIB.

13 RNIB website. *Key information and statistics*. Accessed October 2013.

14 RNIB website. *Key information and statistics*. Accessed October 2013.

15 Action for Blind People website. *Facts and figures about issues around sight loss*. Accessed October 2013..

16 About 10-15% of people who develop AMD have wet AMD.

conditions such as cataract, glaucoma, diabetic retinopathy and certain types of age-related macular degeneration, which can be dealt with most effectively if diagnosed early.

Unavoidable sight loss refers to conditions that are not treatable with current medical knowledge—for example, inherited genetic causes of sight loss.

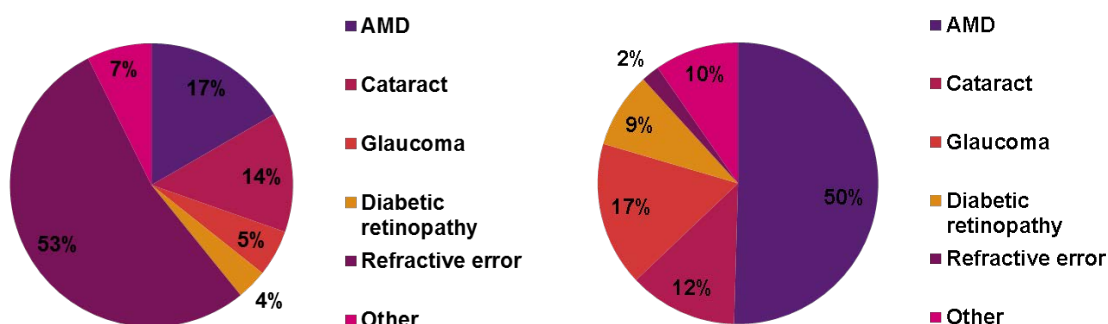
## What causes sight loss?

There are many eye diseases that can lead to sight loss, but the most common causes of sight loss in adults are:

- **Macular degeneration:** an eye condition, usually age-related (AMD), which involves deterioration of the part of the back of the eye responsible for the sharp, central vision needed to read or drive.
- **Cataract:** a clouding of the eye’s normally clear lens, causing vision problems.
- **Glaucoma:** a group of disorders often associated with a raised internal eye pressure, which can damage the optic nerve at the back of the eye and so result in sight loss.
- **Diabetic retinopathy:** damage to the blood vessels at the back of the eye caused by fluctuating blood sugar levels.
- **Refractive error:** an error in the focussing of light by the eye—parallel light rays are not brought to a sharp focus precisely on the retina, producing a blurred retinal image.
- **Inherited eye disease:** this category includes many of the conditions affecting children and young people and leading to progressive sight loss, such as retinitis pigmentosa,<sup>17</sup> Stargardt’s,<sup>18</sup> Leber’s congenital amaurosis,<sup>19</sup> and choroideremia.<sup>20</sup>

Figure 3 shows the main causes of sight loss in adults, the most common of which is refractive error. Figure 4 shows the split between the main causes of blindness in UK adults: AMD is the major cause, followed by glaucoma. Diabetic retinopathy is the leading cause of blindness in working-age adults.<sup>21</sup> Inherited retinal diseases affect 25,000 people (about 10% of all blind people), spread across a number of different eye diseases.

Figure 3: Main causes of sight loss in adults in the UK. Figure 4: Main causes of blindness in adults in the UK.



Source: RNIB (2013) *Sight Loss UK 2013*.

17 Retinitis pigmentosa (RP) is the name given to a diverse group of inherited eye disorders which affect the retina.

18 Stargardt disease is a hereditary eye condition that affects the central area of the retina called the macula.

19 Leber congenital amaurosis (LCA) is an inherited retinal degenerative disease characterized by severe loss of vision at birth.

20 Choroideremia is a rare inherited disorder that causes progressive loss of vision due to degeneration of the choroid and retina.

21 Diabetes UK website. *Monitoring your health: Eyes*. Accessed October 2013.

The causes of sight loss for children differ from those for adults. The three most common causes of severe visual impairment and blindness in children are cerebral visual impairment, disorders of the optic nerve, and disorders of the retina.<sup>22</sup>

Ethnicity is a major factor in eye disease, with some groups more at risk than others. Black people have a higher relative risk of developing cataracts and glaucoma.<sup>23</sup> Asian people are more at risk of developing diabetic eye disease than white people.<sup>24</sup>

## What does the public know about eye disease?

50% of sight loss is classified as avoidable, yet the public is not well-informed about the importance of eye health, and the hereditary nature of some of the diseases. A 2012 survey of 4,000 adults in the UK commissioned by the College of Optometrists<sup>25</sup> found that:

- only 35% of adults strongly agree that you can have eye problems without symptoms;
- 29% of UK adults have not heard of age-related macular degeneration (AMD), which is concerning since it is the most common cause of blindness in the UK; and
- 39% of people from black and minority ethnic (BME) backgrounds do not think that they are at higher risk of certain eye diseases due to their ethnic origin.

In 2010, a market research study for the International Glaucoma Association (IGA) asked 500 members of the public between the ages of 40 and 70: 'What, if anything, do you currently know about glaucoma?' Their answers are summarised below:

- 94% had heard of glaucoma.
- 31% knew it was a condition that affects the eye.
- 17% knew it was a potentially blinding condition.
- 6% knew it could be treated.
- 1% knew about free eye tests for family members.

These figures imply that 69% of the population aged 40 to 70 does not know that glaucoma is an eye disease, which is worrying as many in this age group would have come into contact with people already diagnosed with glaucoma. The usual age of onset for glaucoma is over 40, and the incidence increases with age.

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22 Rahi, J. and Cable, N (2003) *Severe visual impairment and blindness in children in the UK*. The Lancet. 362(9393): p. 1359-65.

23 Winyard, S. and McLaughlan, B. (2009) *Cost oversight? The cost of eye disease and sight loss in the UK today and in the future*. RNIB.

24 Winyard, S. and McLaughlan, B. (2009) *Cost oversight? The cost of eye disease and sight loss in the UK today and in the future*. RNIB

25 The College of Optometrists (2013) *Britain's Eye Health in Focus. A snapshot of consumer attitudes and behaviour towards eye health*. The College of Optometrists.

*'These data probably give some indication as to why it is estimated that just 50% of the glaucoma in the UK has been diagnosed, and an estimated 300,000 patients are living in ignorance of their condition as, in the early stages, it is asymptomatic and the only way it can be diagnosed is via an eye health check. Unfortunately, once lost, currently, sight cannot be recovered, which is why an early diagnosis is so important and public ignorance is not helping to resolve this critical issue.'*

**Russell Young, Chief Executive, International Glaucoma Association**

There is a wealth of excellent research on eye disease, which cannot be getting into the hands of the right people at the right time in the right way. However, the sector is united in trying to reduce the prevalence of avoidable sight loss, and it is one of the three outcome areas in the VISION 2020 (UK) Ltd refreshed UK Vision strategy (discussed later in this section).

## **What services are provided for people with sight loss?**

People at risk of sight loss, or already suffering from it, can access a number of services: primary and secondary eye care, and social and community care. Understanding the priorities of blind and partially sighted people is essential to design an effective care system, and initiatives in the visual impairment sector have attempted to capture these. In the next section we discuss six areas relating to the services provided for people with sight loss:

- i. Understanding the priorities of blind and partially sighted people
- ii. The need for joined-up and timely services
- iii. Primary eye care
- iv. Secondary eye care
- v. Social and community care
- vi. Developing a sight loss pathway

## i. Understanding the priorities of blind and partially sighted people

Before addressing the service provision for people at risk of and already suffering from sight loss, it is helpful to understand what people with a visual impairment regard as important. *Seeing it my way*<sup>26</sup> is a set of outcomes that blind and partially sighted people have said are most important to them (Box 4). The intention is that *Seeing it my way* should drive how services are delivered to ensure these outcomes.

### Box 4: *Seeing it my way* outcomes

1. That I understand my eye condition and the registration process.
2. That I have someone to talk to.
3. That I can look after myself, my health, my home and my family.
4. That I receive statutory benefits and information and support that I need.
5. That I can make the best use of the sight I have.
6. That I can access information making the most of the advantages that technology brings.
7. That I can get out and about.
8. That I have the tools, skills and confidence to communicate.
9. That I have equal access to education and lifelong learning.
10. That I can work and volunteer.

These outcomes help frame the following section of the report, which looks at current service provision in the health and social care sector.

## ii. The need for joined-up and timely services

We recognise that visual impairment is a dynamic area and there are many questions around what future services will look like. It is outside the scope of this report to discuss the implications of the wider changes currently affecting the health and social care sector. However, from NPC's research and conversations with experts it is clear that joined-up care is badly needed. Health and Wellbeing Boards, Local Eye Health Networks and Clinical Commissioning Groups need to work together to ensure that people do not lose their sight unnecessarily. These bodies must coordinate to provide timely eye care and ensure that those who have lost their sight are able to access good social care, including emotional and practical support.

Eye care is not well-integrated with other aspects of healthcare, and potential referral routes—for example GPs—do not routinely look for signs of visual impairment, reinforce messages around eye health, or signpost information.

A report which examined why people typically present late with advanced glaucoma found that, for four of the eleven participants interviewed, the optometry appointment in which their condition was detected was their first ever, or first within ten years.<sup>27</sup> The remainder said that they attended regular optometrist appointments. This suggests two points of delay resulting in late presentation: at the level of the patients themselves and in the healthcare system.

<sup>26</sup> UK Vision Strategy website. *Seeing it my way*. Accessed October 2013.

<sup>27</sup> Insidermedicine.com (2013) *Why do people present late with advanced glaucoma?* Accessed October 2013.

### iii. Primary eye care

Primary eye care is provided in the community by optometrists, in over 7,000 practices across the UK.<sup>28</sup> An optometrist examines eyes, tests sight and prescribes spectacles or contact lenses for those who need them. They also fit spectacles or contact lenses, give advice on visual problems and detect any ocular disease or abnormality, referring the patient to a medical practitioner if necessary.

However, 45% of UK adults would not turn to an optometrist first if they experienced an eye problem, despite optometrists being the primary eye healthcare professionals.<sup>29</sup>

Optometrists provide NHS sight testing under the General Ophthalmic Services Contract, a framework initially set up in 1948. Ophthalmic practices provided 12 million free sight tests for eligible people in 2011/12,<sup>30</sup> and the NHS Diabetic Eye Screening Programme is now offering screening to almost everyone diagnosed with diabetes.

NHS and private eye care is delivered side by side, with NHS patients accessing the same level of care as private patients, and minimal waiting periods due to excess capacity. NHS sight tests are only financially viable for optometrists through cross subsidy from spectacle sales. The delivery of eye care by commercial providers is discussed more fully in the section on older people and sight loss.

Optometrists detect and refer about 4% of patients for further treatment and tests, usually via a GP.<sup>31</sup> An increasing number of schemes are attempting to make use of optometrists' expertise and spare capacity to relieve the burden in secondary care, reducing the number of people going to hospital unnecessarily and the input required from GPs. Unfortunately, communication across sectors can be a barrier for optometrists and doctors, who face problems communicating and sharing patient records.

#### Box 5: eye care professionals

**Ophthalmologists** are medical doctors who specialise in eye and vision care.

Ophthalmologists differ from optometrists and opticians in their level of training, and what they can diagnose and treat. Ophthalmologists can practise medicine and surgery.

**Optometrists** are healthcare professionals who provide primary eye care, and are generally the first point of call for anyone experiencing problems with their sight. They examine eyes, test sight and prescribe spectacles and lenses, give advice about visual problems and detect any disease or abnormality. An optometrist is not a medical doctor, but is licensed to practise optometry.

**Opticians** are technicians trained to design, verify and fit eyeglass lenses and frames and contact lenses. They act on prescriptions from optometrists or ophthalmologists, but cannot treat eye disease themselves.

28 Bosanquet, N. (2010) *Liberating the NHS: Eye Care - Making a reality of equity and excellence*. Imperial College London.

29 The College of Optometrists (2013) *Britain's Eye Health in Focus. A snapshot of consumer attitudes and behaviour towards eye health*. The College of Optometrists.

30 For a list of those who are eligible for a free eye test see the NHS choices website, *Am I eligible for a free eye test?* Accessed October 2013.

31 The College of Optometrists (2013) *Britain's Eye Health in Focus. A snapshot of consumer attitudes and behaviour towards eye health*. The College of Optometrists.

#### iv. Secondary eye care

As a medical doctor, an ophthalmologist is licensed to practice medicine and surgery. An ophthalmologist diagnoses and treats all eye diseases, performs eye surgery, and prescribes and fits eyeglasses and contact lenses.

The vast majority of secondary eye care takes place in eye clinics within hospitals, and is administered by ophthalmologists. Here, the NHS is facing a perfect storm: rapidly-growing need; new and emerging treatments that will generate previously latent and ongoing demand for services; and the impact of the high cost of new treatments on budgets. The associated costs and demands on NHS outpatient services are high; ophthalmology has the second-highest attendances in 2011/12.<sup>32</sup>

The traditional methods of dealing with stretched resources—longer waiting lists and increasing periods between appointments—are already in evidence. Research shows that half of all hospitals are unable to treat people with AMD within recommended waiting times, and 80% of clinics fail to see patients within the recommended follow up period.<sup>33</sup> Left too late, the damage from AMD is irreversible. In addition, research from RNIB shows that around 60% of healthcare commissioners have set limits to restrict cataract surgery, which means in practice that people have to cope with sight loss for longer.<sup>34</sup> These restrictive referral criteria are reflected in a national decline in the number of second eye cataract operations in 2011/12, and significant variation in treatment times.<sup>35</sup>

A report from the group Action on AMD has identified key capacity issues,<sup>36</sup> and there is a pressing need for more research into the cost-effectiveness of service models for the treatment of eye disease within the NHS. The Macular Society is trying to undertake a review of this type focussed on treatment of AMD.

The UK has the lowest ratio of consultant ophthalmologists per 100,000 of the general population in the EU.<sup>37</sup> This often means that eye clinics are very busy and ophthalmologists cannot give patients the time or information they need, especially at the point of diagnosis. In this context, Eye Clinic Liaison Officers (ECLOs)<sup>38</sup> provide practical and emotional support and advice to patients as they struggle with the enormous impact of losing some or all of their sight. According to the RNIB, only 8% of registered blind and partially sighted people were offered formal counselling by their eye clinic, either at the time of diagnosis, or later.<sup>39</sup>

The service provided by ECLOs is much-needed: only six in every 100 people supported by an ECLO knew beforehand about all the services available to them, and 37 in every 100 didn't know about any.<sup>40</sup> However, not all eye clinics offer an ECLO service, and in general support for people at this critical point in their life is sorely lacking. This issue is discussed further in the next section.

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32 Health and Social Care Information Centre (2012) *Hospital Episode Statistics: Outpatient, treatment speciality by attendance type: England 2011/2012*. Health & Social Care Information Centre.

33 Macular Society website. *Half of eye clinics fail to meet guidance on waiting times*. Accessed October 2013.

34 RNIB website (2012) *Restrictions on cataract surgery leave thousands risking sight loss*. Accessed October 2013.

35 RNIB (2013) *Surgery deferred. Sight denied. Variation in cataract service provision across England*. RNIB.

36 Amoaku, W. et al (2012) *Action on AMD. Optimising patient management: act now to ensure current and continual delivery of best possible patient care*. Eye 26.

37 Amoaku, W. et al (2012) *Action on AMD. Optimising patient management: act now to ensure current and continual delivery of best possible patient care*. Eye 26.

38 The Eye Clinic Liaison Officer (ECLO) was established to provide information about eye conditions and services plus emotional support within an eye clinic setting.

39 RNIB website. *Key information and statistics*. Accessed October 2013.

40 RNIB and Action for Blind People patient questionnaires at ECLO locations in Wales, London and the South East between 2011 and 2013.



## v. Social and community care

There has been a sharp decline in social care services provided or paid for by local authorities, discussed more fully in the next section. Within this, trends in social care for blind and partially sighted people are particularly concerning. In *Facing Blindness Alone*, the authors report that over the past five years, from 2008 to 2013, there has been a 35% drop in the number of blind and partially sighted people receiving council care and support.<sup>41</sup> As adult social care budgets have been cut, the bar to receiving social care has risen to cover only the top two eligibility bands (substantial and critical, see Box 6), reducing the numbers who qualify. Blind people are suffering disproportionately.<sup>42</sup>

### Box 6: Four levels of need

Four eligibility bands are set out:

- Critical: there is an immediate risk of coming to harm or losing your independence.
- Substantial: there is a significant risk of health and well-being being affected.
- Moderate: there is some risk to health or well-being, in the future, or that you might lose your independence.
- Low: one or two aspects of daily life are hard for you to manage.

The bands include criteria relating to: threat to life; significant health problems; serious abuse or neglect; choice and control over the immediate environment; personal care and domestic routines; work, education and learning; social support systems and relationships; and family and other social roles and responsibilities.<sup>43</sup>

There is a consensus across the sector that assessors do not always understand the real impact of sight loss, and consequently blind and partially sighted people are underserved by the care system, with many not even getting the basic services.<sup>44</sup>

Following receipt of a Certificate of Vision Impairment, the local authority should register and contact the patient to offer rehabilitation support. This is not always done within agreed time limits, and the period for which the support it is offered is insufficient: a false economy as, in the longer-term, care costs are greater if rehabilitation or reablement services are not delivered as broadly as they should be. According to the RNIB, in the year after registration for a CVI, less than a quarter (23%) of those who lost their sight said they were offered mobility training to help them get around independently.<sup>45</sup> Between 2005/06 and 2011/12 there was a 71% fall in the number of adults receiving professional support, including rehabilitation.<sup>46</sup>

41 Kaye, A. and Connolly, P. (2013) *Facing blindness alone. What government needs to do now to stop the isolation of blind people*. RNIB.

42 Kaye, A. and Connolly, P. (2013) *Facing blindness alone. What government needs to do now to stop the isolation of blind people*. RNIB

43 Byron, C., Blake, M. and Bridges, S. (2013) *Secondary analysis of Adult Social Care Data: What can the data tell us about Blind and Partially Sighted Care Users?* NatCen for RNIB

44 RNIB (2011) RNIB response to the Department of Health consultation, 'Caring for our Future'. RNIB.

45 RNIB website. *Key information and statistics*. Accessed October 2013.

46 Kaye, A. and Connolly, P. (2013) *Facing blindness alone. What government needs to do now to stop the isolation of blind people*. RNIB.

In the face of social care cuts and rising thresholds, the level of care afforded to the visually impaired is falling.<sup>47</sup> This has a significant impact on a person's well-being, and can lead to increased isolation, loneliness and depression.<sup>48</sup> 43% of registered blind and partially sighted people say they would like to leave their home more often.<sup>49</sup> Four out of five blind and partially sighted people have difficulties identifying food and medicine labels.<sup>50</sup>

## vi. Developing a sight loss pathway

VISION 2020 (UK) Ltd, an umbrella body for charities working in visual impairment, has produced the *Adult UK sight loss pathway*.<sup>51</sup> The pathway provides commissioners and practitioners with a simple tool to help them enable people with sight loss to get the right support at the right time, from the right person. By setting out the journey across the wider health and social care system, the pathway should enable better partnership working and a smooth transition between services for people with sight loss.

We have expanded slightly on this sight loss pathway to turn it into an eye health pathway (*Figure 5*), with the addition of education and screening. We have included education because research shows that people are not well-informed about eye health. We have added screening because, although there is plenty of capacity in optometry, people do not always feel comfortable going to a high-street shop for their eye care, or they may not have one in their area. NPC's comments on the various stages of the pathway are shown in italics.

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47 Kaye, A. and Connolly, P. (2013) *Facing blindness alone. What government needs to do now to stop the isolation of blind people*. RNIB.

48 McManus, S. and Lord, C., (2012) *Circumstances for people with sight loss: secondary analysis of Understanding Society and the Life Opportunities Survey*. NatCen for RNIB.

49 RNIB website. *Key information and statistics*. Accessed October 2013.

50 RNIB website. *Key information and statistics*. Accessed October 2013.

51 UK Vision Strategy website. *Adult UK sight loss pathway*. Accessed October 2013.

Figure5: Adult eye health pathway

Processes	Systems and structures		NPC comments
1. <b>Education</b>	Campaigns and public education		Importance of eye health explained.
2. <b>Screening</b>	Community-based optometrist		Increase uptake of screening through increased accessibility. Greater integration between primary and secondary eye health provision.
3. <b>Referral</b>	GP, acute hospital services or self-referral		Streamline referral process to ensure timely treatment.
	Optometrist, optician or low-vision service		
4. <b>Diagnosis</b>	Ophthalmologist		Eye clinics are very busy; increase number of ophthalmologists.
	Certificate of Vision Impairment		It can take months/years between diagnosis and early intervention or a CVI being issued.
5. <b>Early intervention</b>	Information and advice—eg, Eye Clinic Liaison Officers, vision support service		Increase provision of information and advice services within eye clinics.
6. <b>Registrations and assessment</b>	Register of blind and partially sighted people		Under-recording makes forecasting demand difficult.
	Specialist visual impairment assessment of social care need		Assessment of needs underestimates impact of sight loss.
7. <b>Early intervention (reablement)</b>	Visual impairment rehabilitation programme		Long-term cost benefit of rehabilitation and reablement is recognised but specialist provision is being cut.
8. <b>Assessment of eligible need</b>	Community care assessment		Bar to eligibility is being raised (to substantial and critical bands).
	Eligible	Non-eligible	
9. <b>Social care support</b>	Community-based social care	Community-based services	Shortage in funding from all sources.
	Statutory funding	No statutory funding	
<b>Following the pathway leads to independent living with full choice and control.</b>			

Source: Adapted from VISION 2020 (UK) Ltd *Adult Sight Loss Pathway*.

## Costs of eye disease and sight loss

The costs of eye disease and sight loss are high and growing, due to increasing prevalence and expensive treatments.<sup>53</sup> In 2011/12, direct and indirect costs of sight loss amounted to almost £8bn (see box 7).

### Box 7: RNIB's estimates of direct and indirect cost of eye disease and sight loss<sup>52</sup>

<b>£2.6bn</b>	<b>Healthcare costs</b> (total direct NHS expenditure on eye health).
£496m	Primary care costs (expenditure on providing primary eye care services, which includes NHS sight tests).
£536m	Inpatient costs (expenditure on providing inpatient ophthalmology services).
£677m	Outpatient costs (expenditure on providing outpatient ophthalmology services).
£370m	Cost of care (cost of providing residential and community care to blind and partially sighted people).
<b>£5.3bn</b>	<b>Indirect costs</b> (total cost of unpaid care, reduced employment and other indirect costs to the UK economy as a result of sight loss).

RNIB's *Future Sight Loss UK 2* report includes projections for sight loss in the UK by 2020, and suggests expenditure due to the big four conditions is set to grow substantially over the next 10 years.<sup>54</sup> Costs will continue to rise as the number of patients increases, because of the long-term nature of some eye diseases, such as wet AMD<sup>55</sup> and glaucoma, as well as the UK's ageing population.

The price of new treatments is high—especially using the new drugs, Lucentis and Eylea, to treat wet AMD—and these costs are unlikely to have been fully factored into budgets by healthcare providers. As these new treatments emerge, demand continues to rise, which means that more patients are attending eye clinics as new injection treatments for other conditions such as macular oedema and retinal vein occlusion are made available. The number of registrations underestimates the number of people with eye disease; for example, there is a significant difference between current government forecasts for the number of people with wet AMD (26,000) compared to that of the Macular Society (40,000).

## Developments in the sector

There is a general shift towards increased collaboration amongst visual impairment organisations—a promising trend that could help the sector to exert a greater influence on future policy. Eye health is being pushed onto the government's radar because of the massive costs associated with it, and the eye sector is coming together and speaking with one voice to a degree that has not been seen before. Some key initiatives are listed below.

52 RNIB (2013) *Sight loss UK 2013: the latest evidence*. RNIB.

53 RNIB (2013) *Sight loss UK 2013: the latest evidence*. RNIB.

54 Minassian, D. and Reidy, A. (2009) *Future Sight Loss UK 2: An epidemiological and economic model for sight loss in the decade 2010-2020*. EpiVision and RNIB.

55 About 10-15% of people who develop AMD have wet AMD. Dry AMD is more common. It usually develops very slowly and causes a gradual change in central vision. Wet AMD can develop very quickly, making serious changes to central vision over a short period of time.

## The UK Vision Strategy

The UK Vision Strategy,<sup>56</sup> an initiative from the umbrella body VISION 2020 (UK) Ltd led by the RNIB, is a cross-sector framework to improve the provision for eye health and sight loss. The strategy has been refreshed in 2013, five years after its launch, to ensure it is fit for the future.

Following a cross-sector consultation, three strategy outcomes and associated priority actions have been agreed. The UK Vision Strategy's three outcome areas are:

- everyone in the UK looks after their eyes and their sight;
- everyone with an eye condition receives timely treatment and, if permanent sight loss occurs, early and appropriate services and support are available and accessible to all; and
- UK society is one in which people with sight loss can fully participate.

## The Clinical Council for Eye Health Commissioning

The Clinical Council for Eye Health Commissioning was formed in July 2013, including organisations from across eye health, to offer united, evidence-based clinical advice and guidance to those commissioning and delivering eye health services in England.

## Royal College of General Practitioners

The Royal College of General Practitioners has chosen eye health, with a focus on ageing and sight loss, as one of its clinical priorities for the next three years until March 2016. It aims to:

- reduce preventable sight loss amongst patients aged 65 and over; and
- provide more effective management of patients with eye conditions.

## Public Health Outcomes Framework

A national eye health indicator has been added into the government's new Public Health Outcomes Framework, a first for the sector.<sup>57</sup> Since 1 April 2013 the government has measured the rate of preventable sight loss, recording the total number of people who are certified as sight impaired or severely sight impaired, and the number of these who have lost their sight from one of the three major causes of preventable sight loss (glaucoma, AMD and diabetic retinopathy). These three diseases account for more than 60% of blindness in the UK, and sight loss from all three is to some degree preventable. The collection, analysis and reporting on this indicator is based at the Certifications Office at Moorfields Eye Hospital, which is funded by the RNIB.

## Local Eye Health Networks

Local Eye Health Networks are being introduced as part of the NHS reforms. They will involve eye health specialists, including optometrists and ophthalmologists, along with patients and commissioners. Their aim is to improve the quality and availability of eye care services.

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<sup>56</sup> UK Vision Strategy (2013) *UK Vision Strategy 2013 – 2018. Setting the direction for eye health and sight loss services*. UK Vision Strategy.

<sup>57</sup> Department of Health (2012) *Improving outcomes and supporting transparency. Part 1A: A public health outcomes framework for England, 2013-2016*. Department of Health.

## What are the main issues facing the visual impairment sector?

Following the scoping research, several big issues emerged.

### Care pathways for people with sight loss

At present, care pathways for people with sight loss are disconnected. Pressures on secondary health and social care have led to a postcode lottery of provision and disjointed and inadequate services. Joining up primary and secondary care to release more capacity at eye clinics for the less routine appointments, and bringing care into the community, would improve the situation. But initiatives to connect care pathways are in their early days: we do not yet know what impact Clinical Commissioning Groups and Local Eye Health networks might have on sight loss services.

### Older people with sight loss

Older people with sight loss face specific issues. They are likely to become more vulnerable and isolated if visual impairment is not diagnosed and addressed. Older people and the healthcare professionals that support them often see sight loss as a natural part of ageing, and as a result older people do not receive the level of support that they need. Older people are usually affected by a number of health issues; if not supported to adapt to living with sight loss they are likely to gradually engage in fewer social activities outside the home, and to lose their independence.

### The impact of sight loss on well-being

During our research, a consensus emerged that the personal impact of sight loss is underestimated, and the emotional and practical support offered is inadequate. We found that the provision of counselling services, low vision services, rehabilitation and mobility training for people with sight loss was highly variable. This patchy provision means some people cannot access services that they need to participate fully in society.

### The impact of sight loss on life chances

The impact of sight loss on life chances is affected by the ability of a person to build sufficient resilience to cope with transition periods. This is particularly important for young people facing the transition from education to employment. Social isolation can be a problem for people with sight loss within mainstream schools and the workplace. Practical issues are also a concern—in particular mobility training, and guidance to help prevent isolation and enable people to be part of the local community.

### Funding for medical research in the eye sector

The UK boasts highly-respected researchers in the eye sector, and there are many exciting developments occurring in medical research. But there is still a long way to go in finding treatments for major eye diseases, and currently sight loss cannot be reversed. However, the sector is underfunded, and research into the eye not prioritised despite the surge in numbers affected by sight loss and increasing costs of treatment.

*Figure 7* summarises the key points for each of these issues, and explores how further research could add to the current body of knowledge.

Figure 7: Key issues facing the sector

Area	Need	Issues	What research would add
Care pathways for people with sight loss	Support varies greatly depending on location. Integrated services not always available. More community-based services to take pressure off eye clinics.	Separation between primary and secondary care systems. Inability of secondary care to meet appointment targets. Reduction in social care provision. Contribution of local eye health networks.	Highlight areas of good practice . Identify opportunities to link up services.
The specific issues facing older people with sight loss	Growing number of older people with sight loss. 1 in 5 people aged over 75 and 1 in 2 aged over 90 are living with sight loss.	Sight loss is seen as a natural part of ageing; people do not seek accurate diagnosis or treatment. Mainstream services for older people are not suitable for those with visual impairment. Need for practical and emotional support.	Identify why unavoidable sight loss is not being picked up, and how investment in preventative services, and joining up services, can improve the experience for older people.
The impact of sight loss on well-being	Support varies greatly depending on location. Impact of sight loss on well-being under-estimated.	Isolation and depression are common problems. Rehabilitation services not adequate. Mobility training and support is required across all age groups. The benefits of early intervention are not recognised.	Highlight good practice which allows visually impaired people to fully participate in society.
The impact of sight loss on life chances: education	64% of visually impaired children are educated in mainstream schools. Reduce social isolation of young adults through peer support and emotional support.	Potential to improve long-term quality of life and the ability to work. Transition periods are difficult for the individual and their families, and require more support. The benefits of early intervention are not recognised.	Identify the special needs of visually impaired pupils and how these can be met in mainstream education and in the community.
The impact of sight loss on life chances: employment	Two thirds of registered blind and partially sighted people of working age are not in paid employment. Work brings improvement in quality of life, well-being and independence.	9 out of 10 employers rate visually impaired as either difficult or impossible to employ. Getting blind people into work is also an issue of mobility: 180,000 blind people never go out. Transition periods are difficult for the individual and their families, and require more support.	Identify why the visually impaired can't get jobs and how this can be addressed by the individual and the employer.
The funding and state of medical research in the eye sector	50% of sight loss is avoidable. Growing numbers of people are affected by sight loss. Some major eye diseases do not currently have a cure.	Research is not prioritised by the public, government or medical research sector. Major charities in sector do not fund research. The UK is a world leader in eye research, for example through the UCL-Moorfields partnership. Recent results of priority-setting partnership.	Analyse funding for eye research compared to other conditions. Identify how survey into research priorities can influence funders of medical research in future. Identify barriers to growth.

## Evaluating and selecting issues for further research

The scope of our research project required us to narrow down the issues listed above to select two for in-depth research. To do so, we evaluated each to try to understand where our research could have the greatest impact.

This evaluation considered:

- the need, including the size of the population involved;
- existing research coverage, or where there are gaps in research; and
- the degree to which the issues overlapped with other sectors.

The fastest-growing group of people affected by visual impairment is older people. We decided to focus on this area, particularly as the expanding ageing population means the particular challenges associated with older people with sight loss will only increase in scale in the future. The second area selected—the funding and state of medical research in the eye sector—was chosen because many major eye diseases do not currently have a cure, and the sector at first glance appears to be underfunded.

However, all the issues listed above merit further research, and there are many interesting opportunities for further research which unfortunately lie outside the scope of this project.



# OLDER PEOPLE

## Introduction

For older people with significant visual impairment, even the simplest tasks can become unmanageable. Everyday actions that we take for granted—identifying different tablets, reading sell by dates on food, completing forms—are almost impossible to those with poor vision. Getting out and about becomes a struggle: crossing the street is much more dangerous when you cannot see the traffic, or even the edge of the kerb, and finding your way around without the aid of maps or familiar landmarks is hard. People with sight loss often experience poor balance and can be at greater risk of falls.

Inability to read or watch TV can be a particular blow to an older person living alone. Social situations can become a worry as it gets difficult to recognise familiar faces. Some people may choose to avoid situations where they feel uncomfortable or unsure of themselves, which can mean not connecting with friends and becoming increasingly house-bound; 45% of visually impaired people experience access difficulties outside the home.<sup>58</sup> Increasingly cut off from interaction with others, older people with visual impairment can begin to feel lonely and depressed.<sup>59</sup>

It's a bleak picture of shrinking horizons: but it doesn't need to be. If visual impairments are identified and treated early enough, or integrated better into health and social care provision, this isolation and loss of confidence can be avoided. Simple adaptations to living conditions—large print books, or better lighting—can allow people to continue to enjoy the activities they love. Early diagnosis of visual impairment is crucial: some conditions, such as cataracts, can be corrected or treated, but carry the risk of sight deteriorating if left untreated. Others, such as dry AMD, have no treatment or cure—but early diagnosis makes adapting to gradual loss of sight far less daunting, and people can be supported properly to learn to cope as their vision changes.<sup>60</sup>

Loss of vision in old age should not automatically mean losing one's independence, confidence, social life, or hobbies. We have focussed on older people and visual impairment because we feel it is an area where there is real potential to improve.

### Box 8: Older people and sight loss

One in five people aged over 75 is living with sight loss.

One in two people aged over 90 is living with sight loss.

The number of people in the UK with sight loss is set to increase with population ageing: by 2050 the number of people with sight loss in the UK could be nearly four million.

58 McManus, S. and Lord, C. (2012) *Circumstances of people with sight loss*. NatCen and RNIB.

59 McManus, S. and Lord, C. (2012) *Circumstances of people with sight loss*. NatCen and RNIB.

60 Lord, S., Smith, S. and Menant, J. (2010) *Vision and falls in older people: risk factors and intervention strategies*. Falls and Balance Research Group, Neuroscience Research Australia.

## Why focus on older people?

We decided to research the needs of older people with visual impairment for several reasons.

- Visual impairment becomes more common with age. Focussing on this area helps us to understand the experiences of a majority of visually impaired people.
- A large proportion of older people experiences sight loss. Improvements in the diagnosis and care of older people with visual impairments would impact around 1.5m people.
- The UK has an ageing population. Caring for and supporting older people with visual impairment will become increasingly expensive as the number of people requiring specialist services rises. Deteriorating vision contributes to declining welfare and loss of independence.
- Visual impairment is often seen as a natural part of getting old. Changing the perception of visual impairment—encouraging affected individuals and professionals to see it as a condition requiring a response—could help improve the lives of people affected.

## The structure of this section

For all visually impaired people, the particular issues to do with visual impairment intersect with wider issues of access to health and social care. This section should be read in conjunction with the report overview, which puts visual impairment into the wider context of UK healthcare—although a detailed discussion of the UK health and social care system is outside the remit of this report.

This section addresses four questions:

1. What are the issues for older people?
2. What is the role of the charity sector?
3. What can make a difference?
4. What are the funding opportunities?

# 1. What are the main issues for older people?

Some of the issues faced by older people with visual impairment have specific implications related to age; others are common to all visually impaired people—but older people make up the majority of this population. In this section, we highlight issues faced by older people with sight loss in the context of the *Adult UK sight loss pathway*, before exploring them in more depth.

The *Adult UK sight loss pathway*, developed by VISION 2020 (UK) Ltd,<sup>61</sup> sets out the journey across the wider health and social care system with reference to sight loss. In *Figure 5* in the overview, we expanded on the pathway to turn it into an eye health pathway, with the addition of education and screening. *Figure 8* shows a version of the pathway adapted to explore specific problems faced by older people. We have added comments in italics on issues relevant to older people at each stage of the pathway.

Figure 8: Adult eye health pathway with reference to issues for older people

Processes	Systems and structures	NPC comments on the eye health pathway issues for older people
1. <b>Education</b>	<i>Campaigns and public education</i>	<i>Awareness of lifestyle risk factors that may affect sight in older age. Recognition of the importance of getting eyes tested in older age. Recognition from individuals and professionals that sight loss need not be accepted as a natural part of ageing.</i>
2. <b>Screening</b>	<i>Community-based optometrist Other health care professionals</i>	<i>Older people often have multiple health problems. All healthcare professionals working with older people should look for signs of visual impairment to encourage referrals for testing and diagnosis.</i>
3. <b>Referral</b>	GP, acute hospital services or self-referral	<i>Accessibility issues in attending appointments. Other health conditions (eg, arthritis) can compound access difficulties associated with visual impairment.</i>
	Optometrist, optician or low vision service	
4. <b>Diagnosis</b>	Ophthalmologist	<i>Where older people are in medical or care settings (hospitals, care homes) accurate diagnosis of visual impairment is essential as it has implications for treatment and care.</i>
	Certificate of Vision Impairment (CVI)	
5. <b>Early intervention</b>	Information and advice, eg, ECLO (Eye Clinic Liaison Officer), vision support service	<i>As with younger people, emotional and practical support is crucial after the point of diagnosis.</i>
6. <b>Registrations and assessment</b>	Register of blind and partially sighted people	<i>Awareness of how visual impairment can interact with other medical and social care conditions to influence level of support required.</i>
	Specialist visual impairment assessment of social care need	

61 UK Vision Strategy website. *Adult UK sight loss pathway*. Accessed October 2013.

7. <b>Early intervention (reablement)</b>	Visual impairment rehabilitation programme		<i>Rehabilitation needs to be sufficient, focussed not only on personal care but also on helping people undertake daily tasks.</i>
	Eligible	Non-eligible	
8. <b>Assessment of eligible need</b>	Community care assessment		<i>Appropriate assessment, which does not underestimate the challenges of visual impairment.</i>
	Eligible	Non-eligible	
9. <b>Social care support</b>	Community-based social care	Community-based services	<i>Social care (residential or home-based) is adapted to the needs of visually impaired older people. Community-based services for older people are adapted and accessible to visually impaired people.</i>
	Statutory funding	No statutory funding	
<b>Following the pathway leads to independent living with full choice and control.</b>			

Source: Adapted from VISION 2020 (UK) Ltd *Adult Sight Loss Pathway*

Looking at the pathway above, three broad issues emerge:

- i. older people wait too long to engage with eye care services, for a number of reasons;
- ii. visual impairment may not be adequately understood by professionals; and
- iii. the support needed to adjust to visual impairment is not available.

The first two points relate to concerns around diagnosis and access to visual impairment support services; issues that affect those with treatable and earlier stage visual impairments, as well as those with more severe visual impairment. The final point concerns adapting to life with a visual impairment, which is a more serious issue for those with a severe visual impairment—often those that qualify to be registered as blind or partially sighted.

### **i. Older people wait too long to engage with eye care**

Older people may delay engaging with the eye care services that are available to them, for a number of reasons:

- they underestimate the implications of their deteriorating eyesight;
- they see sight loss as a natural part of getting older; or
- they distrust the commercial aspect of primary eye care.

#### **Older people may underestimate the implications of their deteriorating eyesight**

Between 12% and 50% of older people have undetected sight loss, and may be suffering a host of negative side effects that could be prevented.<sup>62</sup> Often, older people don't appreciate the seriousness of sight loss, and the huge impact it could have on their lives, so do not seek help or treatment. People with undetected sight loss are more likely to be isolated and depressed, to need assistance with daily living, to suffer impaired memory, and to rate their own health more poorly.<sup>63</sup> Sight loss is associated with a range of negative emotional outcomes. People with sight loss are six times as likely to feel depressed as those with no impairment, and eleven times as likely to feel that their confidence is low. More than two in five people with sight loss struggle to make ends meet—twice as many as those with no impairment. People with sight loss are

62 Iliffe, S., Kharicha, K. and Myerson, S. (2009) *Research Findings 21: Obstacles to improving visual health in older people*. Thomas Pocklington Trust.

63 Iliffe, S., Kharicha, K., Harari, D., Swift, C., Gillman, G. and Stuck A. (2013) *Health risk appraisal in older people 6: factors associated with self-reported poor vision and uptake of eye tests in older people*. BMC Family Practice.

more likely to have difficulty accessing transport, and to need assistance with everyday activities.<sup>64</sup> While the severity of sight loss varies, its impact on people’s health, emotional well-being, financial circumstances and daily life should not be underestimated—least of all by older people.

### Older people see sight loss as a natural part of ageing

As people age, they lower their expectations of their sight. Visual impairment, particularly gradual sight loss, tends to be seen as a natural—and by extension inevitable—part of ageing. Research indicates that 50-70% of sight loss in older people (ie, sight loss caused by refractive error or cataracts) is preventable or treatable.<sup>65</sup> RNIB recommends that people over 60 have annual sight tests, but less than half of this population group do so. When asked why they had not had a sight test, most people said they felt they had not had a problem with their eyes.<sup>66</sup> When sight deteriorates gradually, people may not realise the problem warrants specific attention. This means that many older people are not making best use of the sight they have. Sight loss may be a functional, rather than an absolute, condition; some within the visual impairment sector suggest that the language of sight loss needs to change to help people recognise that the problems they experience can be addressed.

*‘We need new ways of talking about sight loss so that people don’t assume we’re only interested when sight loss is absolute—we try and talk in terms of “I don’t see too well anymore”.’*

Nicola Venus-Balgobin, Project Manager, Sense

A review of visual impairment noted the high level of treatable conditions in older people, concluding that *‘information is required on signs and symptoms of treatable conditions’*.<sup>67</sup> Charities and specialists are producing high-quality information, which reaches an audience of people who have recognised their need and sought support. But often these messages do not reach a wider population. There is currently limited focus on discussing eye health as a lifelong concern, or understanding and communicating lifestyle risks associated with sight loss to people at a younger age.<sup>68</sup>

Healthcare professionals can also share the assumptions of older people that decreased capability is a natural part of ageing, which can affect decisions made about people’s care. However, from May 2013, addressing preventable sight loss is now a key public health indicator, and local authorities are required to report on the number of people certified as blind or partially sighted due to preventable conditions.<sup>69</sup> This may incentivise a more proactive approach to addressing preventable eye conditions.

### Older people distrust the commercial motives of primary eye care

Older people can be discouraged from accessing sight tests by the commercial nature of optometry. Often a high street optician is the first stop on the way to diagnosis and treatment, but many people see them as a business selling a product, rather than a healthcare service. Sight tests are vital for picking up early warnings

64 McManus, S. and Lord, C. (2012) *Circumstances of people with sight loss*. NatCen and RNIB.

65 Tate, R., Smeeth, L., Evans, J. and Fletcher, A. (2005) *The prevalence of visual impairment in the UK; A review of the literature*. RNIB.

66 Conway, L. and McLaughlan, B. (2007) *Older people and eye tests: Don’t let age rob you of your sight*. RNIB.

67 Tate, R., Smeeth, L., Evans, J., Fletcher, A. (2005) *The prevalence of visual impairment in the UK; A review of the literature*. RNIB

68 For example, research has linked intake of oily fish to a lowered risk of age related macular degeneration—see Centre for Ageing and Public Health, London School of Hygiene and Tropical Medicine (LSHTM) (2008) *Research Findings No 16: Oily fish intake and age-related macular degeneration*. Thomas Pocklington Trust.

69 Department of Health (2013) *Public Health Outcomes Framework 2013 to 2016 and technical updates*. Department of Health.

of serious eye conditions, and maintaining an accurate prescription to correct sight loss caused by refractive error. Sight tests are free for people over 60, but less than half of those eligible take advantage of this. Fear of the cost of purchasing glasses is one of the key barriers to people accessing eye care, particularly for those with low incomes. In focus group research, older people identified a conflict between the optometrist's medical role in diagnosing their needs, and their sales role in encouraging them to spend money. Some worry that they will feel pressurised into purchasing expensive frames, or be embarrassed to ask for the lenses to be replaced in their existing frames.<sup>70</sup> These themes are consistent in different studies of the barriers to eye tests, but older people's views do vary. Although these barriers are important for some older people, there is a spectrum of responses to a number of factors that influence decisions around accessing sight tests, which help understand the views of older people (see *Figure 9*).

Figure 9: Visual impairment in later life: a model of factors influencing decisions and actions



Source: *Research Findings 21: Obstacles to improving visual health in older people*. Thomas Pocklington Trust

### Older people experience difficulties around certification and registration

Registering as sight impaired or severely sight impaired entitles people to access a number of benefits. The process of registration and certification is described in the overview section, alongside some of the barriers.<sup>71</sup> An offer of registration is made by the local authority once a Certificate of Vision Impairment is received from the NHS. On receiving a Certificate of Vision Impairment older people often feel a sense of shock;<sup>72</sup> particularly people with remaining functional vision who had not previously thought of their visual impairment as extreme. Some experts we spoke to feel that because the offer of registration is made while people are still experiencing this shock, they may be less likely to register out of a feeling that they can cope adequately, or out of an unwillingness to identify as 'blind'. Ophthalmologists may choose to spare older people the emotional upheaval of certification, believing that there are few benefits in doing so (for example, older people are unlikely to be working and able to take advantage of tax credits). However, registration serves to bring

70 Biddyr, S. (2011) *Preventing sight loss in older people: Barriers and enablers to the uptake of regular sight tests*. RNIB.

71 See Overview, p. 9.

72 Freeman, C. *An investigation into the emotional consequences of visual impairment in old age*. Research proposal.

someone to the attention of social care services, and without referral, older people may miss out on timely assessment and specialist support.

The process of certification and registration occurs when sight loss is at a 'certifiable' level and cannot be treated. This means that many older people with treatable visual impairments that affect their quality of life, such as cataracts or macular disease, are not eligible for the benefits of registration whilst they are awaiting treatment.

## ii. Visual impairment may not be adequately understood by professionals

By the age of 60, almost 60% of people are living with at least three long-term health conditions.<sup>73</sup> Often, older people are in regular contact with healthcare professionals, providing opportunities to identify indicators of undiagnosed visual impairment, reinforce messages about eye health, and signpost information. The Thomas Pocklington Trust has supported research to investigate how GPs and nurses can be encouraged to think about visual impairment when discussing other health problems with older people.<sup>74</sup>

At present, eye health and sight loss are not well integrated with other aspects of healthcare. Within the visual impairment sector there is a perception that other conditions 'pull focus' from vision, which is considered a less acute need. For example, people qualifying for health and social care support are allocated a specialist who takes primary responsibility for their care. Where people experience multiple health difficulties, the primary worker will be a specialist in the most acute condition, which means people may be less likely to be working directly with a vision rehabilitation worker.

There are a number of areas where inadequate understanding of visual impairment in professional healthcare can be a problem:

- recognition of visual impairment with specific health conditions;
- recognition of visual impairment in medical and social care settings; and
- problems securing adequate health and social care support.

### Recognition of visual impairment with specific health conditions

**Strokes** can affect the part of the brain that deals with vision, in a condition called hemianopia. The individual loses one side of their vision, but the brain does not recognise that this has happened. Up to two thirds of people experience difficulties with vision after a stroke.<sup>75</sup> There is no cure for hemianopia, but individuals can be taught a 'scanning' technique where they move their head to maintain the field of vision. During hospital care, simple adjustments can be made, such as ensuring that the patient is located where they can see people approaching their bed from the ward entrance and food placed on the side of the bed. If hemianopia remains undiagnosed, people can suffer inappropriate hospital care; if not taught the scanning technique they will be at risk in situations such as crossing the road, where they may be unaware of traffic approaching.

**Dementia** may mean that people have difficulty communicating with healthcare professionals about their sight loss, which can in turn exacerbate the symptoms of dementia. For those affected by dementia, unfamiliar environments increase disorientation. Untreated visual problems accentuate this difficulty, preventing people from finding visual 'anchors'.

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73 Department of Health (2012) *Third Edition of Long Term Conditions Compendium*. Department of Health.

74 Iliffe, S., Kharicha, K. and Wijeyekoon, S (2013) *Research Findings No. 37: Improving uptake of eye care among older people: developing a training programme for GPs*. Thomas Pocklington Trust.

75 Stroke Association website, *Visual problems after stroke fact sheet*. Accessed October 2013.

There is also a risk that professionals working with older people misinterpret the symptoms of sight loss and confuse them with those of dementia.<sup>76</sup> The symptoms can be similar: disorientation, inability to recognise people, and difficulty following conversations. In some cases, people who have lost a lot of their sight can suffer visual hallucinations (known as Charles Bonnet syndrome), which can be misinterpreted as hallucinations related to dementia. Actions can be taken to minimise the effect of hallucinations due to sight loss. It is important to be able to differentiate between the two and accurately assess sight, and therefore vital that people with dementia and those caring for them ensure that sight is tested regularly.

### Recognition of visual impairment in medical and social care settings

In all settings where older people are in contact with health or social care professionals, their sight loss may have implications for appropriate care. If sight loss is not recognised, or adaptations are not made, the individual's quality of care can be severely impaired.

**Hospitals** need to be aware of visual impairment as a possible cause of accidents leading to a hospital stay for older people—for example, after a fall. Failure to address this underlying cause will mean the problem is not averted in future. Hospitals must adhere to good practice to support inpatients with visual impairment—for example using coloured cups so that water can be easily identified. All those involved in an individual's care should be aware of any visual impairment, and adjust their care accordingly. For example, they may need to ensure that all the information the patient needs is explained verbally, including making sure the patient knows where their food has been placed.

**Home care** providers delivering food or personal care support should be aware of clients' visual impairments so that they can make appropriate adaptations: failure to do so can leave people extremely vulnerable in their own homes. For example, if people are not pre-warned of staff changes, and are unable to visually check identification documents, they have the choice of allowing a stranger into their home, or going without support. Home care complaints procedures are often inaccessible to people with visual impairments; for example, sometimes they are provided only in small print format.<sup>77</sup>

In recent months, the level of social care offered has been widely criticised, with Leonard Cheshire Disability campaigning to put an end to home care visits that last just 15 minutes and which cannot possibly support people adequately.<sup>78</sup>

**Care homes** are one setting where staff have huge influence over the support available to residents, and recent research found that eye care is neglected in residential care homes.<sup>79</sup> There is no standard requirement for care homes to ensure appropriate eye healthcare and sight tests for all residents, and in many care homes eye health and sight is ignored; staff do not see the lack of eye care as a threat to health, and are not trained to understand its importance. Care home residents are often unaware of their need for better sight care, and do not ask for it. Following recent research, a coalition of sensory loss charities has written to the Care Quality Commission to request themes inspections on sensory loss to be carried out in care homes.

<sup>76</sup> University of Bradford (2010) *Research Discussion Paper No 8: Improving vision and eye health care to people with dementia*. Thomas Pocklington Trust.

<sup>77</sup> Equality and Human Rights Commission (2012) *Close to Home: Review of evidence around visual impairment*. EHRC.

<sup>78</sup> Leonard Cheshire Disability (2013) *Disabled people forced to choose between staying thirsty and going to the toilet*. Press release. Leonard Cheshire Disability.

<sup>79</sup> Watson, J. and Bamford, S. (2012) *Undetected sight loss in care homes: an evidence review*. Thomas Pocklington Trust and International Longevity Centre.

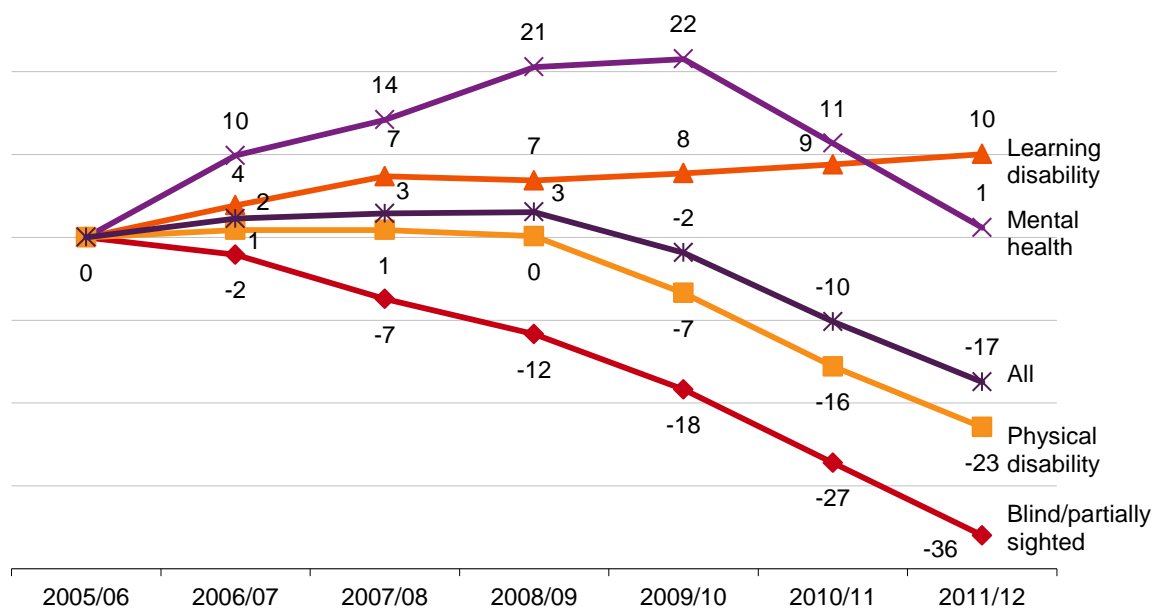


### Problems securing adequate health and social care support

Social and community care services for visually impaired people vary between local authorities. Local authorities have statutory responsibilities under the social care duty framework, but most authorities share the budgetary pressures that are causing services to be cut.

**Vision services can be seen as a ‘soft target’ for authorities needing to make savings, and blind and partially sighted people have been disproportionately affected by a recent decline in services.** Many authorities are tightening the criteria for provision of statutory services—for example, offering support only to those categorised as having ‘critical’ needs,<sup>80</sup> and cutting access to community services such as meals at home, day centres and transport. Analysis of adult social care data reveals that the decline in health and social care services seen since 2005/06 has been greatest for blind and partially sighted people; a 35% decline, compared to 22% for people with a physical disability, and 16% for all service users (see *Figure 10*).<sup>81</sup> The disproportionate decrease covers almost all service types: residential and nursing care, and community-based services. The biggest decline has been in meals, professional support and day care. The decline in community-based services has been greater for older than for younger blind and partially sighted people.<sup>82</sup>

Figure 10: % change in number of people receiving any community-based service by disability type.



Source: Secondary analysis of Adult Social Care Data, NatCen and RNIB

**There is a shortage of specialist rehabilitation workers.** To receive appropriate health and social care support, older people with visual impairment need to work with sensory specialists, and have their needs assessed by people with a real understanding of the impact of visual impairment. The visual impairment sector has lobbied for rehabilitation support to be available under the reablement agenda prior to any assessment of needs being made,<sup>83</sup> so the assessed level of need is not a criterion for access to reablement support, and

80 See Overview p. 17 box 6 for definition of different levels of need.

81 The exception to the picture of declining services is in direct payments, which have increased across all client types, but increased less for blind and partially sighted clients than for other client types.

82 Byron, C., Blake, M. and Bridges, S (2013) *Secondary analysis of Adult Social Care Data: What can the data tell us about Blind and Partially Sighted Care Users?* NatCen for RNIB.

83 RNIB (2013) *Facing Blindness Alone: What Government needs to do now to stop the isolation of blind people.* RNIB.

assessments are made once a person has been supported to maximise their independence. In practice, this does not always happen. Statutory guidance<sup>84</sup> requires that anyone assessing the needs of deafblind person must be trained to do deafblind assessments; the charity Sense reports that some local authorities have recruited specialists in response to this requirement, but coverage remains patchy.<sup>85</sup>

**Methods of sensory assessment are not well-integrated into mainstream practice;** most assessment tools make only brief reference to sensory issues, and this may be insufficient to identify the level of support needed as a result of visual impairment. This is particularly problematic when assessors share assumptions about visual impairment being a natural part of ageing, as discussed above. Assessments tend to focus on physical mobility challenges, rather than sensory; for example, people may be asked if they can go to the toilet independently, rather than whether they are able to navigate to a toilet independently. As a result, the support needs of visually impaired people are liable to be underestimated in assessment.<sup>86</sup>

**Those with dual sensory loss face additional problems.** Coping strategies for single sensory loss often rely on the other senses working harder to compensate; audio readers can support those who are unable to read printed materials; and those with hearing loss may rely on lip reading. But where both senses are impaired, implications for the individual are profound; the impact of losing both senses is 'more than the sum of its parts'. If the condition is not formally recognised, individuals may not be offered appropriate support.

*'When we run training sessions for social care professionals we often hear people say "I assessed someone this morning and noted that they had difficulty seeing and hearing, but it didn't occur to me until now that we should be supporting them as a deafblind person".'*

Sue Brown, Head of Public Policy, Sense

Most local authorities have sensory rehabilitation teams. Sensory rehabilitation workers can be part of a disability team located within adult services, which may be separate from older people's services. In other cases, the local authority may have one team for care planning (including social workers and physical disabilities), and a different team for complex needs (including occupational therapy, sensory disability, and extra care housing). In either case, the low number of sensory rehabilitation workers often means that they cannot be involved in the care of all those within the authority known to be affected by visual impairment, and decisions about where visual impairment sits can affect the authority's ability to identify people with sight loss across its other services. One way to counter this problem is for sensory rehabilitation workers to share their expertise with those conducting assessments and with occupational therapists, which can help to embed awareness of visual impairment across the authority's health and social care activity. However, with the current pressure on budgets, specialists may hesitate to share expertise for fear of making it easier to cut specialist services.

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84 Department of Health (2009) *Social Care for Deafblind Children and Adults*. Department of Health.

85 Personal communication with Sue Brown, Sense.

86 RNIB (2013) *Facing Blindness Alone: What Government needs to do now to stop the isolation of blind people*. RNIB.

## Box 9

### Case study: London Borough of Barking and Dagenham

The London borough of Barking and Dagenham employs four sensory specialists, all of whom work within its Occupational Therapy and Sensory Unit. Two of these staff are fully qualified Visual Impairment Rehabilitation Officers, and a third specialises in work with people who have dual sensory loss. This integration was implemented in 2010 to make sensory work more 'mainstream' and, through a programme of training, briefings, and informal discussion, the expertise of the sensory specialists is being shared with the wider team. This ensures that occupational therapists are more alert to sensory issues when working more generally with older people.

People interviewed for this research stressed the need to get visual impairment onto policy agendas and into legislation, so that local provision of care and support is adequate and standardised. The Care Bill currently going through parliament, if passed, will give local authorities preventative responsibility for health care.<sup>87</sup> It is not yet clear what impact this will have; experts interviewed expressed concern that the Care Bill does not specify who should receive preventative support, or at what level.

### iii. The support needed to adjust to visual impairment is not available

Gradual sight loss may go unacknowledged for some time, but people affected often react to a growing sense of vulnerability by changing their behaviour to avoid situations where they lack confidence or feel unsafe. This results in a gradual 'narrowing of the circle' in which people live.<sup>88</sup>

## Box 10: Tactile communication

People with dual sensory impairment rely on tactile communication. This is easier to teach when people are still able to receive audio and visual information. Once people have lost almost all their sight and hearing, highly-skilled practitioners are needed to support people to learn tactile communication.

It is much easier for people to maintain their independence as their sight deteriorates if they can learn coping techniques early in the process—rather than trying to re-incorporate activities into their routine that they have decided are off limits. This is particularly true for older people, who can find it more difficult to retain what they have learned. Recognising a visual impairment as early as possible, and adapting to living with reduced vision, is crucial to retain independence. The benefits of early action are vast: people who are not connected to the world and the things they enjoy will age more quickly, and become more vulnerable. However, it can be difficult for people to accept the reality that their sight is likely to continue deteriorating.

Visual impairment has myriad effects on a person's life, so support to adjust takes many forms and addresses a variety of areas, including:

- support to avoid isolation;

<sup>87</sup> Care Bill 2013-14, available at [www.parliament.uk](http://www.parliament.uk).

<sup>88</sup> Ball, C. (2013) *Services and support for older people with sight loss: Expert briefing*. RNIB.

- dealing with the emotional impact of visual impairment;
- practical adaptation to living with a visual impairment; and
- reablement and ongoing support.

### Support to avoid isolation

60% of women and 36% of men aged 75 and over live alone. 44% of all blind and partially sighted people reported that they felt cut off from people and things around them.<sup>89</sup> For older people, the risk that sight loss will lead to isolation is more acute; many older people live alone without strong networks of friends and social contacts.

Visual impairment can result in physical isolation. With severe sight loss, people tend to walk less—nearly 50% of older people with sight loss say they always limit the amount of walking they do outside their house.<sup>90</sup> The combination of visual and other health problems (including frailty associated with age) makes it more difficult for older people with sight loss to get out and about; 60% of older people with sight loss reported that they needed someone to help them get out of the house. For people who have relied on sight to navigate, even a short walk to the shops is daunting—around 30% of people over 75 with sight loss feel able to go to the corner shop, let alone use public transport; just 30% of those of retirement age with sight loss could hail a bus.<sup>91</sup> Physical isolation leads to social isolation as people lose contact with friends and social groups.

Confidence is key for people to learn how to get around with limited sight. Without support, people can be in danger of slipping into a vicious cycle: they find it difficult to leave the house and access services or social groups, which in turn means they are less exposed to the kind of information and peer support that might help them become more confident to get out and about independently.

*'I see such a difference between people of the same age who lost their sight at a young age, and those who lost it in older age. One of the men who attends our group is very happy to go to new places alone, and to ask for help if he needs it. The people who lost their sight in older age are more reluctant to ask for help.'*

**Tina Johnston, Older People's Services Coordinator, Blackfriars Settlement**

Visual impairment also affects people's ability to communicate effectively, and can cause isolation even where people appear to be in social situations. People may not be able to recognise whether someone is speaking to them, and find it particularly difficult to participate in group conversations. In care homes, staff may not be aware that visual impairment makes it more difficult for people to engage with activities. They may assume that the individual chooses to be withdrawn, and not consider the adaptations necessary for that person to participate.<sup>92</sup>

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89 Pey, T., Nzegwu, F. and Dooley, G. (2006) *Functionality and the Needs of Blind and Partially Sighted People in the UK: An interim report*. Guide Dogs.

90 Gjonça, E. and Nazroo, J. (2005) *An investigation of the circumstances of older people with sight loss: Analysis of the English Longitudinal Study of Ageing*. Thomas Pocklington Trust.

91 Ball, C. (2013) *Services and support for older people with sight loss: Expert briefing*. RNIB.

92 Cooper, S. (2013) *Research Discussion Paper No. 13: How can care homes 'look out' for eye health?* Thomas Pocklington Trust.

Physical mobility barriers which make it more difficult for people with visual impairment to navigate outside their home also make it more difficult to attend regular medical appointments, visit an optometrist, and access the support and care which could improve their quality of life. Other conditions associated with older age, for example arthritis, can exacerbate this difficulty.

## Box 11

### Case study: Finding your Feet

The RNIB Finding your Feet course provides a space for visually impaired people to discuss the issues of getting out and about. Participants think together in a safe environment about overcoming the barriers they face. By sharing experiences, participants are encouraged to try things they might otherwise not have attempted, such as using a white stick, or engaging in new hobbies.

## Dealing with the emotional impact of visual impairment

Losing your sight has huge emotional implications. More than a third of older people with sight loss are affected by depression.<sup>93</sup> The repercussions of this are widespread; confidence and mental health have a significant impact on mobility.<sup>94</sup> Many people feel overwhelmed by their sight loss and the challenges they face to adapt to it.

Sight loss in later life can be understood using 'grief models', commonly applied to understand bereavement. Grief at loss of sight has a profound emotional impact, which can have a fundamental impact on identity and ability to function. It is vital that services provide people with support to adjust to being diagnosed as blind. Professionals delivering diagnosis, and working with people immediately afterwards, have an important role to play in minimising distress and helping people adjust. For many people the experience of diagnosis can be brusque and deal only with the medical aspects.<sup>95</sup>

Eye Clinic Liaison Officers (ECLOs) work with people receiving diagnosis, helping them come to terms with their diagnosis and connecting them to the support available, bridging the medical (hospital and eye clinic) and community settings. There is no consistent model for ECLO provision: they may be provided by the NHS, charities, or the local authority. ECLOs are recognised by eye care professionals as a valuable and effective resource to help people adjust to living with visual impairment,<sup>96</sup> but are present in only around a quarter of eye clinics and ophthalmology departments. Another quarter have some other form of 'early intervention' support, but this leaves more than half of all eye clinics and ophthalmology departments with nobody to support people at the point of diagnosis or certification, and no support to connect individuals with the services available to them.

## Practical adaptation to living with a visual impairment

There are many physical adaptations that can be made to help an older person make best use of their remaining sight. Key among these is the use of low vision aids such as magnifiers and adaptations in lighting. People over 60 need three times more light to see than a 20-year-old, and will take longer to adjust to

93 McManus, S. and Lord, C. (2012) *Circumstances of people with sight loss*. NatCen and RNIB.

94 Pey, T., Nzegwu, F. and Dooley, G. (2006) *Functionality and the Needs of Blind and Partially Sighted People in the UK: An interim report*. Guide Dogs.

95 Freeman, C. *An investigation into the emotional consequences of visual impairment in old age*. Research proposal.

96 Subramanian, A., Conway, M. and Gillespie-Gallery, H (2011) *The role of the Eye Clinic Liaison Officer*. RNIB.

changes in light. With suitable lighting, older people with visual impairment find it easier to complete household tasks, and are able to complete tasks they previously could not have.<sup>97</sup> Buildings designed with the needs of visually impaired people in mind can have contrast colour schemes to help people navigate, and other design features to support coping strategies which rely on other senses or memory.<sup>98</sup> Low vision aids can help people to read and engage in other activities requiring close vision, but are only recommended for use over short periods of time.<sup>99</sup> People can also benefit from tactile or audio clocks and watches, and big button telephones.

Cooking can present a huge challenge for people who have lost their vision—particularly those who find themselves living alone after the death of a partner or carer, and who perhaps have not previously cooked for themselves. Some support services include safe cooking courses; many people rely on microwave meals for ease and safety which do provide valuable assistance but can leave them with fewer options for healthy eating, and a lack of interest and variety in their diet.

*‘It’s not just about being healthy; people lose the joy of eating a variety of foods.’*

**Tina Johnston, Older People’s Services Coordinator, Blackfriars Settlement**

Technology can provide real solutions and opportunities to help people with sight loss, but needs to be the right kind of technology for older people to engage with and feel confident using. Generally speaking, access to technology can be difficult for older people with a visual impairment. For those who find it difficult to leave the house, the internet is a key resource: for information in accessible formats, and for engaging in social interaction, for example through email or video calls, to reduce feelings of isolation. But many older people do not have access to this technology in their homes, computer skills to find the information they need, or access to the hardware and software which makes the internet accessible to people with sight loss. Not all the adaptations which can make internet technology accessible are widely known and understood; even where people are aware of technological adaptations, they may be expensive to purchase. Learning to use the internet, like many new skills, is more difficult in older age, and harder still with restricted vision. The dual problems of a lack of access and lack of skill can make it difficult to engage with essential services that are increasingly delivered online: paying bills, or applying to move into more suitable accommodation. Charities and funders might like to look into the opportunities that technology can offer in more detail.

### Reablement and ongoing support

Reablement is a process of acquiring the new skills to help maximise independence when adapting to life with a visual impairment. A reablement programme might include learning to navigate outside and within the home, safe cooking skills, and learning to use a range of aids and adaptations. Reablement studies have shown that this investment can lead to a decreased reliance on social care, and deliver value for money.<sup>100</sup> However, the level of reablement support provided is often inadequate for people’s needs—it often lasts just six weeks and focusses on personal care at the expense of daily tasks.<sup>101</sup> The lack of ongoing support beyond this six-week window can put older people at particular risk if their sight or health deteriorates, or their support network changes, for example through the death of a partner.

97 Cooper, S. (2013) *Research Discussion Paper No. 11: Improving lighting, improving lives*. RNIB.

98 School of Architecture, University of Sheffield (2011) *Extra care housing for people with sight loss: lighting and design*. Thomas Pocklington Trust.

99 RNIB website. *Our new range of magnifiers*. Accessed October 2013.

100 RNIB (2013) *Facing Blindness Alone: What Government needs to do now to stop the isolation of blind people*. RNIB.

101 RNIB (2013) *Facing Blindness Alone: What Government needs to do now to stop the isolation of blind people*. RNIB

There is also a lack of follow-up or ongoing support in clinical medical services, which leaves people '*coping alone or fearing abandonment*'.<sup>102</sup> If someone is diagnosed with an eye health condition, they may not be advised that they could experience additional eye problems in the future, and will not be routinely called back to check how their eye health is progressing.

There are therefore a number of points at which an older person with a visual impairment could 'drop out' of the eye care system, and have no professional support network if their condition deteriorates. The new eye health pathway aims to address this by linking health and social care into a single pathway that incorporates emotional support. Provided the pathway is taken up and used by stakeholders such as the NHS and local authorities, older people with visual impairment should benefit.

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<sup>102</sup> Cooper, S. (2013) *Research Finding 38: As life goes on: a closer look at how support services respond to the changing needs of people with sight loss*. Thomas Pocklington Trust.

## 2. What's the role of the charity sector?

Charities often deliver services for older people and visually impaired people that are publicly funded, and their work can overlap with that of the public sector. This section explores the role of the voluntary sector in delivering non-statutory services. Below we outline a number of the services the voluntary sector provides, illustrated with case study examples.

### Specialist services in the community

Specialist community services such as befriending, social activity groups, or day centres are an important part of an individual's social network, and can provide an early warning if people are not coping well or experiencing depression.

*'One of the guys who comes to the group gets quite down sometimes. If he doesn't come one week I'll give him a call and I won't hang up until I've cheered him up. If we're really worried, one of the volunteers will pop in and see him.'*

**Tina Johnston, Older People's Services Coordinator, Blackfriars Settlement**

#### Box 12

##### Case study: BlindAid

For 180 years, BlindAid has provided a home-visiting befriending service for isolated visually impaired people. In each of the 12 inner-London boroughs, a member of staff visits 50 visually impaired people on a fortnightly basis. The charity also provides a telephone support service, distributes audio equipment, and employs a welfare rights officer. The people BlindAid supports are often the oldest and most vulnerable visually impaired people; those who rarely, if ever, leave their homes. All of BlindAid's services are provided free at the point of use.

The charity has identified a need for community-based support for people who are currently isolated but have the capacity to rejoin society. BlindAid will shortly open a new centre in Southwark offering social activities, including art and dance, and skills courses, like healthy eating and IT. The centre will be based within a disability resource centre, with access to the borough's sensory team and opportunities to try out visual aids. BlindAid is partnering with Dial-a-ride and recruiting volunteers to offer guides from a number of journey points.



## Research, information and tools

Providing research, information and tools contributes to professional understanding of the needs and experiences of visually impaired people. This informs the practice of charities, ensuring that the services and information they provide meet the needs of visually impaired people.

### Box 13: Research, information and tools

**RNIB** has taken a leading role in developing best-practice guidance and policy briefings for health and social care providers.

**Thomas Pocklington Trust**, a specialist housing provider for people with visual impairment, publishes extensive research on a range of issues affecting visually impaired people.

**Guide Dogs** is currently funding research into emotional support for people recently diagnosed with sight loss, through a Randomised Control Trial (RCT) conducted by the University of Cardiff.<sup>103</sup>

**Sense** has developed a screening tool for dual sensory loss for use in care homes.<sup>104</sup>

## Person-centred approaches

Person-centred approaches are important to many charities that build on individuals' interests and capacities. This may mean involving users in service design, or building the capacity of individuals to campaign and represent their own interests. There is evidence that group-based problem-solving in a health education programme is an effective intervention, with lasting effects on the individuals involved.<sup>105</sup>

### Box 14: VISAL

**VISAL** is a toolkit to increase civic engagement and confidence in visually impaired older people.

The toolkit provides a resource for groups who want to support visually impaired older people to be motivated to engage in civic participation, and overcome barriers to doing so. It contains detailed guidance for running programme sessions. It was developed and tested by a partnership of seven European charities, including UK partners Age UK and the RNIB.

## Cross-sector working

Cross-sector working between the visual impairment sector and the older people's sector is essential, since there is such an overlap between the people they work with. Charity sector provision of community services for visually impaired older people is overstretched, but most communities have provision for older people which could be

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103 Cardiff University News Centre (2011) *Studying visual impairment and depression*. Cardiff University website.

104 Pave, S., Patel, M., Hodges, L., Douglas, G. and McGee, A. (2012) *The Identification and Assessment of the Needs of Older People with Combined Hearing and Sight Loss in Residential Homes*. University of Birmingham, Sense, Bupa.

105 Binns, A. et al. (2009) *Low vision service outcomes: a systematic review*. Prepared for RNIB as part of the Low Vision Service Model Evaluation (LOVSME) project.

adapted to the needs of visually impaired people. For example, most public buildings are physically accessible to disabled people, but staff and volunteers at day centres and lunch clubs are not always trained in guiding people around the facility, or ready to plan inclusive activities. Increasing accessibility requires extra resources—such as staff or transport—which can be a challenge.

The visual impairment sector is already engaged in joint working with other charities, health services and other public services to use existing infrastructure to effectively reach and support older people with visual impairment. Both RNIB, as the leading organisation for visually impaired people, and Age UK, as the leading charity working with older people, have undertaken projects together and with other partners, and joint working seems to be increasing. Important work is happening not just between the older people and visual impairment sides of the charity sector, but also with public services.

#### **Box 15: Examples of cross-sector working**

**Charities working with the NHS:** Sense is involved in pilot ‘social prescriptions’ to people with long-term conditions through social and preventative groups. NHS funds are managed by local voluntary sector organisations, leading to cross-voluntary sector working.

**Sharing of research and practice:** the UK Stroke Forum runs a session on visual impairment at its conferences, and has seen the popularity of these sessions gradually increase.

**Vision 2020 (UK) Ltd** has a dementia and sight loss interest group, which has led to the creation of resources including a fact sheet on cataracts and dementia.

**Innovative projects run jointly between partner charities and public services,** such as the ‘Eyes Right’ eyesight screening tool developed by Thomas Pocklington Trust and RNIB, and used by the Fire and Rescue Service’s (FRS) existing home safety visits in Staffordshire.

This good practice is not yet embedded across the older people and visual impairment sectors. There are structural issues that make it more difficult for the sector to collaborate in a systematic way; several charities working with older people operate decentralised, local branch models, including Age UK and the Alzheimer’s society. Effective collaboration relies on good relationships between partners, and it is very difficult to replicate local good practice across a network of independent organisations.

### 3. What can make a difference?

All areas of healthcare are facing questions about the ageing population and the role charities can play. The visual impairment and older people sectors must take this opportunity to develop a clear response.

Older people with a visual impairment can be a very vulnerable, isolated part of the community, and often face significant barriers to having their voices heard. The charities that support visually impaired older people, whether visual impairment specialists or not, have a vital role in speaking up and strongly advocating people's right to participate in society. Charities also have significant convening power, and a strategic position that provides opportunities to share expertise across different stakeholders involved in the support, treatment and care of visually impaired older people. Existing medical, health and social care structures determine many of the experiences of visually impaired older people, but charities can still play an important part in improving their quality of life. The following section contains some ideas about how charities and funders could make a positive difference in this area. These are presented as suggestions for discussion, and the roles of convenor and of advocate are strong themes.

This research has identified two areas of work that we feel could make a positive difference:

- i. investing in preventative and early intervention services; and
- ii. developing joined-up ways of working across different parts of the charity and public sectors.

NPC recognises that it may not always be possible to demonstrate the cost benefit of some interventions but believes that increasing a person's wellbeing is a justified end in itself which should not be overlooked.

#### i. Investing in early intervention services

Early intervention and preventative work is vital for all people who are losing their sight, but particularly for older people who may be experiencing other health problems that make them more vulnerable. Below we describe five steps that could be taken to improve prevention and early intervention in visual impairment:

- provide strong public eye health messages;
- address barriers to older people accessing eye tests;
- promote person-centred approaches to maintaining independence;
- support people to navigate certification and registration; and
- make the case for reablement services.

##### **Provide strong public eye health messages**

Lifestyle factors that increase the risk of sight loss are not widely publicised, and many people do not consider eye health a priority. Many healthcare professionals working with older people do not prioritise vision in their assessment of needs. The impact of this is seen most often in the older population, but the problem is one of choices and circumstances throughout people's lives, and messages should be addressed to all ages.

A clear public health campaign could challenge the assumption that sight loss is a natural part of ageing, and emphasise the benefits of eye health throughout life. The campaign could address both lifestyle risk factors (for example, the importance of wearing wraparound sunglasses in direct sunlight, the benefits of a good diet), and the value of regular eye examinations in diagnosing and preventing sight loss.

A campaign of this type would require input from a broad coalition of charities, agreeing and communicating consistent messages. Funders could support the campaigning activity, but also the coalition building.

## Address barriers to older people accessing eye tests

Failure to seek eye tests is a key barrier for older people receiving diagnosis and accessing appropriate support. Many older people lack confidence visiting a high street optometrist—somewhere with which they may have no previous relationship. Some optometrists may appear to be less suited to older people, due to the cost of the frames they stock, and the way they market their services. Older people may feel uncomfortable visiting somewhere that primarily targets a younger audience, and worry about the cost of eye tests and glasses.

Eye tests are free for people over 60, and those who receive income benefits are eligible for support towards the cost of lenses and frames. Many retailers offer very low-cost frames—for example, Tesco offers frames for £15—but lenses can still be expensive.<sup>106</sup> Cost is a real problem, but culture and lack of confidence are also to blame. Bringing optometrists into the GP surgery, a trusted place where older people feel comfortable, is one response.<sup>107</sup> This approach can be effective, but requires motivation on both sides to develop a solution that is not necessarily financially rewarding. To make a difference at scale, we need to use existing infrastructure, thinking about places that older people already trust and visit to seek health support.

One approach would be to build on the 'Brief intervention' model where pharmacists act as a first point of contact, proactively offering support. 'Brief intervention' trials include offering advice on alcohol consumption during emergency contraception appointments.<sup>108</sup>

Charities could broker conversations with optometrists, GPs, and commercial providers to investigate different models to address the barriers to eye tests, or create initiatives to encourage older people to get their eyes tested annually—but arrangements need to benefit all parties to be sustainable. Charities can also ensure the people they work with are aware of their right to free eye tests, and the availability of low-cost frames and lenses. The 'brief Intervention' approach would be best tested with academic support to evaluate its impact; funders keen to support this could seek academic partners.

### Box 16

#### Case study: Boots

Boots is working to promote eye health by highlighting how eye health is closely related to general health, and how lifestyle choices can impact eye health as well as vision. The company is working to improve referrals between its opticians, hearing care and pharmacy services. Colleagues are being trained to help patients identify lifestyle factors that might influence eye health, as well as providing advice and information. Boots is currently linking this work into the anti-smoking 'Stoptober' campaign; its optometrists will inform smokers of the risks of smoking to their eye health, and encourage them to access services to help them quit smoking.<sup>109</sup>

<sup>106</sup> Tesco Opticians website, accessed October 2013.

<sup>107</sup> For example, the partnership between Exmoor Medical Centre and Max Davison Opticians, where an optician visits the surgery to perform eye tests every Wednesday.

<sup>108</sup> Durham University School of Medicine, Pharmacy and Health Completed Projects: Alcohol brief intervention in pharmacies. Durham University website, accessed October 2013.

<sup>109</sup> Boots website. *Eye health at Boots opticians*. Accessed October 2013.

## Promote person-centred approaches to maintaining independence

Experts we spoke to emphasised the need for ongoing support, particularly emotional, as the most significant need for older people with visual impairment. This need is crucial at the point of diagnosis, when people are making emotional and practical adjustments to their condition; there is a successful model for initial support in the form of ECLOs, although coverage is incomplete.

Even where ECLOs are present, their role is to connect people with the community provision available to them, and sufficient provision is not always there. Investing time and resources upfront can help people stay independent and reduce reliance on more costly services later. People need an ongoing connection to support services to prevent them ‘falling out’ of the system, so that if circumstances change they receive help to adjust again, rather than beginning to deteriorate.

This support should be tailored to the individual, helping them strike the right balance to live a fulfilling life at a level of independence that is safe for them. The emotional journey after diagnosis varies between individuals, and everyone will experience peaks and troughs. Structured, prescriptive services are not appropriate; people need flexible support that recognises their individual preferences and needs.

*‘We look past the disability to find out what our members are interested in, and find ways to help them achieve this. It’s about making people feel important and loved, and giving them a sense of responsibility or a role to play for the group. We’re encouraging people not to be scared of things, not to lose their spirit and determination.’*

**Tina Johnston, Older People’s Services Coordinator, Blackfriars Settlement**

Involving people with sight loss in defining and designing services keeps their needs and aspirations at the centre, and avoids inaccurate assumptions about their preferences. Older people may not prioritise adjustments and adaptations in the same way that younger people do. Some will have a limited appetite to learn new skills. These views and limitations should inform service design.

Charities and funders should support the provision of ECLO services to offer valuable support at the point of diagnosis. Visual impairment specialist charities should aim to provide flexible programmes of support, working with individuals to help them live enjoyable and rewarding lives. This might involve supplementary skills and reablement work, regular social groups, and befriending. Ideally people should be able to dip in and out of services when they feel in need of support.

## Support people to navigate certification and registration

A Certificate of Vision Impairment (CVI) allows access to a number of benefits and concessions.<sup>110</sup> Visual impairment has been associated with financial hardship,<sup>111</sup> which can be exacerbated by failure to access entitlements. The shock which many people feel on receiving a CVI can affect their decision to register with their local authority; initially many people feel they are still able to cope, and are uncomfortable being thought of as blind. Local authorities are not required to ask people to confirm again whether they are happy with their decision not to register.

Older people that have received a CVI could be supported by charities to think through the implications of their diagnosis—particularly financial implications—and supported to complete paperwork and undergo registration

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<sup>110</sup> See Overview p. 9 box 3.

<sup>111</sup> McManus, S. and Lord, C. (2012), *Circumstances of people with sight loss*. NatCen and RNIB.

assessments. Welfare officers are a valuable resource for charities to support the people they work with, and ensure they feel confident to continue through the process of registration.

### **Make the case for reablement services**

As health and social care budgets are restricted, decisions are increasingly based on urgency or acuteness of need. There is a risk that visually impaired older people who do not qualify for reablement activity, or for whom available reablement is insufficient to develop skills of independence, will find it difficult to care for themselves; these difficulties may increase if their visual impairment deteriorates. People may go on to develop a level of need that would qualify them for social care support, which may have been avoided if they had received adequate reablement support in the first place. Without sufficient health and social care support, their health may deteriorate to a point of requiring medical care or treatment, with the cost borne by the NHS. Both NHS and social care authorities have an incentive to invest in preventative care.

Local authorities may recognise this argument, but, faced with difficult spending decisions, require evidence that an intervention will deliver value for money before they pay up. Local authorities would be more ready to invest in preventative services if they were able to quantify long-term savings against initial investment—but it is expensive and time-consuming to demonstrate causal links in a situation affected by so many varied factors. Existing literature discusses the risks if older people with visual impairment are not properly supported, for example linking loneliness to health,<sup>112</sup> and recent research explores the case for preventative support for working-age disabled adults.<sup>113</sup> At present, the economic evidence is inconclusive: some studies have shown that reablement reduces use of social care,<sup>114</sup> but a recent review of low vision services identified a lack of evidence on the cost-effectiveness of interventions, which could inform policy.<sup>115</sup> Despite the challenges of making a watertight economic case for investment in reablement services, organisations working in this field must continue to build the evidence base around the importance of adequate reablement to allow people to maximise their independence. This is why RNIB and the Thomas Pocklington Trust, amongst others, prioritise the social research that can start to provide the evidence for effective interventions.

## **ii. Developing joined-up working across the charity and public sectors**

The standard response to the problems faced by visually impaired older people is that they need information: about the importance of identifying and diagnosing sight loss, about rights and entitlements, about adaptations which could be made to their homes, and about community services which offer social interaction and help adjust to life with a visual impairment. A lot of high-quality information does exist: the challenge is ensuring that people have access to it at the right time.

*Figure 11* shows some of the points in an older person's care where a visual impairment could be picked up and diagnosed. There is a pressing need for the visual impairment sector to become more integrated with wider health services and charities working with older people, so that individuals and professionals understand how important visual impairment is to an individual's overall care.

112 McManus, S. and Lord, C. (2012), *Circumstances of people with sight loss*. NatCen and RNIB.

113 Aiden, H. and Bush, M. (2013) *Ending the other care crisis: Making the case for investment in preventative care and support for disabled adults*. The National Autistic Society, Mencap, Leonard Cheshire Disability, Sense, Scope.

114 RNIB (2013) *Facing Blindness Alone: What Government needs to do now to stop the isolation of blind people*. RNIB.

115 Binns, A. et al (2009) *Low vision service outcomes: a systematic review*. RNIB.

Figure 11: Referral routes: warning signs for visual impairment



Source: based on interviews, and drawing on Thomas Pocklington Trust Research Findings No. 37: Improving uptake of eye care among older people: developing a training programme for GPs.

Better integration within the visual impairment sector, and with wider health and social care services, is discussed below with reference to three areas:

- cross-sector working;
- building generalist knowledge while preserving specialist skills; and
- policy change.

### Cross-sector working

Charities working with older people, and charities working with visually impaired people, are aware that their beneficiaries overlap. There is an opportunity for organisations such as Age UK, which works in all aspects of older people's lives, to help integrate eye health into wider views about older people's health and well-being. Partnerships could embed vision as a core part of the 'ageing well' agenda.

There are pockets of cross-sector working, but vision is not yet a routine part of work with older people. Small organisations may be driven to make their services accessible to individuals with a visual impairment who want to use their facilities. Larger organisations may take a more strategic approach, driven by leadership that recognises the need to meet the needs of the community, and offer a suitable service to older people with sight loss in receipt of direct payment support (personal budgets). Effective partnerships require considerable investment of time and resources. Even where organisations have an awareness of each other's work, working together is not always easy. But if done well, partnerships can have a very positive impact.

## Box 17

### Case study: Seeing it from their side

RNIB, Age UK and Action for Blind People have been working together in local partnerships to share good practice for supporting older people with sight loss.

Age UK Lincoln has been working in partnership with Action for Blind People to ensure its services are suitable for, and supportive to, visually impaired older people.

Age UK Lincoln hosts a member of staff from Action for Blind People, who has provided visual awareness training for members of Age UK staff, as well as working closely with the information, advice and guidance officers to support clients with a visual impairment to lead an independent life. RNIB Everyday Living products have also been introduced into the general working of the organisation where appropriate. These can be tried by visiting older people and purchased if desired.

Age UK and RNIB have hosted two seminars to share insights from the local projects, in Leeds and London, and hope that such a service can be replicated in other parts of the country.

Charities and funders could seek opportunities to initiate or support programmes to build partnerships, and share expertise about how best to support visually impaired older people and ensure mainstream services are accessible. Charities and funders also have great power to convene the diverse stakeholders involved in supporting older people; from medical, health and social care, and commercial backgrounds, as well as from different parts of the charity sector. Those keen to support visually impaired older people should look out for opportunities to educate different stakeholders about best practice for their support.

### Building generalist knowledge while preserving specialist skills

The most efficient way to support older people with visual impairment would be for all services working with older people to be aware of visual impairment needs—a bottom-up approach. A commitment to human rights should require residential and community support services to ensure they are suitable for people with visual impairment, as for any disability. Sensory practice should be integrated across social care, to ensure visual problems, or the specific needs of visually impaired people, are not neglected.

Health and social care professionals working with older people need to be more aware of visual impairment, to know how to recognise the symptoms, and how this should inform services. Sight should be seen as an important part of a person's whole care. A shift in attitudes is needed to embed the use of basic good practice in health and social care settings, as discussed earlier in the chapter.

Primary care staff should also raise awareness among patients that sight loss is not inevitable, and may be addressed medically (with sight tests or glasses), technologically (with adaptations to houses), and through information and skills (for example safe cookery and mobility skills).

Increased awareness by staff would promote smoother referrals between different health services. Vision 2020 (UK) Ltd has developed the *Adult Sight Loss Pathway* (see overview), but many people still 'drop out' of eye health care. Improved referrals across primary, secondary, social care and community services could help make this framework a reality for individuals, combining medical, emotional and health and social care support.

In practice, this means providing training to up-skill staff so that visual awareness is a core part of staff training. Training works best if accompanied by ongoing support, such as a peer network. Training costs



money, and not all care or support facilities will be motivated to invest in staff development, but subsidised provision could encourage uptake.

Specialists remain an important part of this system; people with a deep understanding of the impact of sensory impairment should be involved in the assessment and care of those affected by such problems. Inevitably, people with more generalist remits will not give the same level of attention to visual needs as someone dedicated to visual impairment. But with intense resource pressure and growing need, delegation of tasks from more highly-qualified specialists could provide more cost effective care:

- There is already a shortage of ophthalmologists to meet the medical needs of people with visual problems, which causes delays and difficulty accessing procedures such as cataract operations. With advances in technology, there may be roles that could be delegated to optometrists, allowing ophthalmologists to concentrate on the practice areas where their specialist medical qualifications are essential.
- In health and social care, a similar discussion can be had about the role for visual specialists, and whether some of their work could be delegated to others in regular contact with an individual—for example, occupational therapists, assistant rehabilitation workers, health visitors, or people providing personal care at home.

In both cases, relevant stakeholders must agree clear boundaries, and decide which areas of care can be safely delegated without compromising quality. Parties need to work together and overcome concerns about devaluing the role of the specialist, to make best use of resources available and ensure high-quality specialist care is available where needed.

### Policy change

Policy change is a top-down approach to getting visual impairment onto healthcare agendas for all older people. This may be stricter regulation around accessible services, or getting visual health recognised as a priority for a local authority by lobbying to include it in an area's Joint Strategic Needs Assessment. It may involve lobbying care standards regulators (such as the Care Quality Commission) to adopt thematic assessments that include visual impairment as an area of specific focus. There may be a need to strengthen the existing evidence base to add weight to campaigning messages.

The voluntary sector has the independence to campaign for these changes, and an opportunity to draw on 'user voices' in its campaigns: something that can be very powerful alongside a strong evidence base.

*'We campaigned to have attacks on a guide dog recognised as equivalent to an attack on the individual. We showed MPs a video of a visually impaired mother and her daughter discussing their experience when the mother's guide dog was brutally attacked. The effect was more powerful than anything we could have told them.'*

**Carl Freeman, Policy Manager, Guide Dogs**

Moving visual impairment up the agenda for policymakers and service commissioners requires a coordinated effort across the visual impairment sector and others involved in older people's care. Charities' independence allows them to play a powerful advocacy role. The recently launched Commission on the Voluntary Sector & Ageing<sup>116</sup> is bringing together organisations across the sector to provide long-term strategic thinking about how best the sector can prepare for and adapt to an ageing society in the next 20 years. We hope this kind of collaboration can help draw attention to issues such as visual impairment and older people.

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116 See <http://voluntarysectorageing.org/>

## 4. Funding opportunities

There are a number of opportunities for funders interested in visual impairment and older people. Below, we suggest some areas we believe would benefit from investment.

### Research

#### Making the case for preventative services

**Growing the evidence base for preventative services that aim to promote well-being and help people maintain independence.** The challenges of developing a watertight cost benefit analysis have been discussed above, but the visual impairment sector should continue to invest in research and evidence reviews to demonstrate the value of reablement services in economic and human welfare terms. The analysis would be a valuable campaigning tool to get reablement services onto policy agendas, and could encourage discussions about budget pooling for preventative care amongst NHS and local authorities.

#### Access to health and social care services

**Investigation into the hypothesis that the erosion of specialist sensory provision is negatively affecting visually impaired older people's experiences of the health and social care system.** If nobody involved in an individual's care has a deep understanding of the impact that visual problems can have on people's lives, social care needs assessments will be made without complete understanding of an individual's circumstances. We do not have concrete figures for how far specialist provision has been cut within local authorities, so this research could begin by benchmarking the level of change, before investigating what impact this has had.

#### Lifestyle risk factors

**Literature review of lifestyle factors associated with risk of sight loss.** Work in this field has been piecemeal, so a small piece of work could begin to scope the public health messages around 'seeing well throughout your life', and identify gaps in current knowledge.

### Services

#### Support community based support services

**Support charities to provide valuable community support services;** some are primarily social and others focus more specifically on developing skills and resilience. These may not be innovative projects, but they are highly valued by users, and increasingly important as thresholds for accessing social care support tighten. Funders could look for services that take a person-centred approach, involving users in service design, and offering support in a flexible way that is responsive to different individual needs and aspirations.

#### Build visual impairment capacity of mainstream older people's services

**Helping mainstream older people's organisations adapt to meet the needs of visually impaired people.** There will never be comprehensive coverage of specialist visual impairment services, but despite cuts, most areas have community provision for older people in the form of lunch clubs, social groups, and day centres. Joining mainstream older people's services is a cheaper way to support visually impaired older people with lower level needs. If all older people's services were accessible, then visually impaired people could exercise choice over where they spend their leisure time.

## Training

### **Training health and social care professionals to support visually impaired people**

One way to ensure that health and social care professionals across older people's services understand the needs of visually impaired people is to provide training accredited as CPD (Continuing Professional Development). The need for training is well-recognised within the sight loss sector, but not necessarily in wider health and social care. For training schemes to really influence how an organisation or service operates, training needs to happen at all levels and be followed up with ongoing support, allowing people to share experiences and ideas to overcome barriers. Where possible, more than one person from an organisation (for example, staff in a care home) should attend the training, to help embed changes across the organisation and prevent knowledge being lost when individuals move jobs. There is no need to re-invent the wheel; many training materials exist, but ongoing funding is needed for them to be delivered and supported.

## Campaigning

### **Campaigning for legislative and regulatory change**

Funders could support charities to engage in campaigning work to achieve legislative and regulatory change, getting visual impairment more prominently embedded in the healthcare agenda. Funding campaigning offers less certainty of a result, but the impact on the lives of all those with visual impairment is potentially huge. This approach will only be effective if the visual impairment sector can unite behind a coherent campaign with clear goals.

## Older people: Conclusions

- Visual impairment is often seen as a natural—and therefore inevitable—part of getting older. Many people develop lower expectations of their sight and do not seek medical treatment, or start adapting and using low vision aids, as it deteriorates. Healthcare professionals can share the view that sight loss comes with ageing, and don't necessarily recognise the huge impact that vision, or loss of it, can have on a person's overall health and well-being. This means that older people miss opportunities to address their visual impairment, maximise their sight and improve their well-being.
- The high proportion of older people affected by visual impairment means that everyone working with older people should be alert to it: to recognise where people are experiencing visual impairment; to ensure medical treatment and care is appropriate; and to ensure that community and social care services are adapted to be accessible. A good understanding of visual impairment is important for charities working with older people, GPs, hospital staff and health and social care professionals.
- Adapting to sight loss requires considerable support: emotional support to help people adjust to the shock of diagnosis and sudden sense of loss; practical support to help them make adjustments to their home and routine; and support to develop the skills needed to live independently. Without this support, older people with visual impairments risk losing their independence needlessly, and finding themselves unable to engage in activities they enjoy. This can have a negative effect on well-being, as well as financial implications for the state in the cost of support for those who are not supported to live independently.
- Charities in the older people's and the visual impairment sector can work together, share expertise, and improve the support offered to visually impaired older people. The visual impairment sector can also work with medical and health and social care professionals to ensure they understand the needs of visually impaired older people. Much can be done at grassroots level, but to effect change on a wider scale the sector must continue to lobby and campaign to ensure visual impairment is understood and taken seriously in medical and health and social care contexts.

# MEDICAL RESEARCH IN THE EYE SECTOR

## Introduction

Being diagnosed as blind or partially sighted today can mean a permanent loss of sight. At the moment, once the ability to see is gone, it is often gone forever—with cataract surgery being the major exception. Yet there may be a time in the not-too-distant future when, in the majority of cases, sight loss can be reversed: when medical treatment is able to give someone back their vision.

Medicine is changing and advancing all the time, and new discoveries at the most basic molecular level have implications for all kinds of seemingly incurable diseases and irreversible conditions. Eyes are no different: we understand much about the way they work, but there is far more that could be explored. We don't know the causes of many eye diseases, and have no treatment for others. Research can throw new light on why visual impairment and sight loss occur, and how to cure or prevent them.

But medical research in the eye sector is underfunded. Sight is not prioritised, either by government, or the public, who donate in droves to charities researching other common medical conditions, but do not seem to connect with loss of vision in the same way. Yet, as we have seen in the previous chapter, visual impairment can have a huge impact on people's lives, and people have a very real fear of losing their vision. The growing scale of the problem could help create more of a sense of urgency around the issue.

We need to fund the right kind of research in the right way, to ensure new discoveries get from the lab to the clinic and into the lives of people with visual impairments. Investment in medical research is an area where there is great potential to make a huge difference to the lives of millions of people affected by sight loss. It is ripe for investment and improvement, and there is much that charities and funders can do.

### Box 18: What is meant by medical research?<sup>117</sup>

Medical research is undertaken to support and develop the body of knowledge within a specific field of medicine. It begins with basic medical research at the level of cells and molecules, to increase knowledge about processes in the body and other living organisms, before moving on to drug discovery and development. This feeds into pre-clinical research (research carried out on treatments before they can be tested on human participants) and clinical research (which typically uses human participants to test treatments). Recently, there has been an increasing focus on translational research which bridges the gap between basic research and a deliverable product. This process is shown in *Figure 12*.

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<sup>117</sup> Some research does not neatly fit into this definition, for example adherence to glaucoma eye drops. The research is not developed in the lab through the examination of cells yet it is about prevention and treatment of eye disease.

Figure 12: The medical research process



## Why focus on medical research?

Medical research was selected as a topic for further research for three reasons:

- People with sight loss not only want to be able to play a full role in society, but more fundamentally they want their lost sight back. This is not currently possible for many eye diseases and will only become possible with advances in medical research. As the population increases, and ages, the number of people affected by sight loss will also increase. The need to prevent sight loss and restore lost sight will continue to become more and more pressing.
- Funds available for medical research into sight loss are disproportionately low on a number of measures, leading to the view across the sector that sight loss is not being prioritised.
- A number of recent developments in the sector, including the UK Vision Strategy (discussed in the *Overview* section of this report) and the adoption of the national eye health indicator, point towards growing recognition of sight loss as a major problem. This momentum should be capitalised upon. However, the level of public knowledge around eye disease is low, and we lack a sense of urgency which could be harnessed to raise funds for research.

## The structure of this section

This section is in three parts:

1. What are the issues surrounding medical research?
2. What can make a difference?
3. What are the funding opportunities?

## 1: What are the issues surrounding medical research?

This part of the report discusses the following issues surrounding eye medical research:

- i. The sector's profile and voice is at a pivotal point.
- ii. Medical knowledge is advancing rapidly, but has further to go.
- iii. Eye research is underfunded.
- iv. Eye research infrastructure is not prioritised.

### i. The sector is at a pivotal point

#### **Cross-sector collaboration has increased**

With over 600 charities alone working in visual impairment, the sector has historically struggled to convey a unified voice. This has hindered campaigning and policy work. But there are signs that the sector is becoming more organised and is starting to speak together: for example, the work of VISION 2020 (UK) Ltd, and the successful lobbying for the adoption of the national eye health indicator into the public health outcomes framework.

However, although collaboration is happening, the potential for medical research to help reduce the prevalence of eye disease through prevention or treatment is still neglected in public debate. The gaps in public knowledge surrounding eye disease, referred to earlier in this report, may go some way to explain the lack of understanding of the importance of medical research into eye disease.

#### **UK eye research is highly rated, and working together to address priorities**

Eye research in the UK is excellent, and recently has made a number of very promising developments. The sector has recently come together to address research priorities for the future.

#### **The eye research sector in the UK is highly respected internationally.**

In 2007, one of the largest eye and vision research centres in the world was founded in London: the National Institute for Health Research (NIHR) Biomedical Research Centre (BMRC) at Moorfields Eye Hospital and UCL Institute of Ophthalmology. The BMRC's task is to conduct 'translational research' designed to take advances in basic medical research from the laboratory into early phase clinical studies. Funding for the centre has been extended to 2017. The BMRC, along with several other research institutions across the UK, has been at the forefront of groundbreaking research in areas including advanced stem cell research and gene therapy.

#### **There has been sustained collaboration and consultation across the sector to set sight loss and vision research priorities.**

In 2012, a group of charities joined together to survey patients, carers and eye health professionals across the UK. Led by Fight for Sight, the largest charity funding eye research in the UK,<sup>118</sup> the initiative aimed to ensure that the research priorities for the future are based upon the needs of patients, family members and healthcare professionals. The results of the national survey organised through the James Lind Alliance<sup>119</sup> were published in the *Sight Loss and Vision Priority Setting Partnership (PSP)*, and are the most comprehensive of any sector

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118 Fight for Sight website. Accessed October 2013.

119 The James Lind Alliance (JLA) is a non-profit making initiative established in 2004. It brings patients, carers and clinicians together to identify and prioritise the 10 uncertainties, or 'unanswered questions', about the effects of treatments that they agree are most important. This helps those that fund health research to be aware of what matters to both patients and clinicians.

to date. The research priorities can be used to help funders target their funds, and researchers demonstrate why their research is important. The PSP produced a list of the top 10 unanswered priority research questions in 12 different categories of eye research.

## ii. Medical knowledge is advancing rapidly, but has a way to go

Eye research has seen some notable recent successes. However, much more research into eye disease is required for a number of reasons:

- there are many different eye diseases where the cause is unknown;
- there are many different eye diseases for which there is no treatment, especially dry AMD; and
- for some eye diseases current treatments do exist but they may not work for everyone. Where there is treatment it cannot always reverse sight loss.

*'We need to find ways of preventing many different eye diseases and we still haven't cracked the holy grail of reversing sight loss.'*

Michele Acton, Chief Executive, Fight for Sight

There have been some notable successes in eye research:

- **Cataracts:** the NHS performs approximately 350,000 cataract operations annually, making this one of the most common surgical procedures in the country. Advances in surgery have enabled this operation to be performed as an outpatient procedure, and most patients go home from hospital a few hours afterwards.
- **Age-related macular degeneration (AMD):** In recent years, a group of drugs (medicines) called anti-VEGF drugs has been developed to treat wet AMD.<sup>120</sup> Treatment with these drugs can help stop the progression of wet AMD, but has only been available in the last five years.
- **Glaucoma:** significant advances have been made in the development of eye drops and surgery to treat glaucoma. Early research at Moorfields/UCL has shown that it may be possible to use stem cells taken from the nose to repair the optic nerve damaged by glaucoma, thus preserving and even restoring sight. Stem cell research being undertaken at Cambridge University is also showing potential to protect the cells damaged by glaucoma.
- **Inherited eye diseases:** research into understanding the genetics of eye diseases is creating opportunities to develop more effective treatments. If a retinal disorder is caused by one defective or missing gene, then replacing that gene with a working copy could prevent sight loss by helping cells in the retina work properly. The Gene Team<sup>121</sup> at UCL Institute of Ophthalmology has found a way to do this using a modified, safe virus to deliver a working copy of a gene into the eye—a development that could have treatment implications for a variety of inherited eye diseases. Clinical trials of this process for Lebers Congenital Amaurosis are underway. In addition, a team at Oxford University is undertaking a gene therapy trial for choroideremia.

Corneal dystrophies are caused by faulty genes, and are currently incurable. Researchers at the University of Ulster and the University of Dundee are undertaking research into a new treatment using a gene therapy technique that could progress to clinical trials in the next few years.<sup>122</sup>

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120 About 10-15% of people who develop AMD have wet AMD. Dry AMD is the more common type of AMD. It usually develops very slowly and causes a gradual change in your central vision. Wet AMD can develop very quickly, making serious changes to your central vision in a short period of time.

121 The Gene Team website. Accessed October 2013.

122 Fight for Sight e-news, August 2013. Accessed October 2013.



Figure 13: Status of big four eye diseases in terms of prevention, treatment and research

Disease	Can sight loss be prevented?	What is the treatment?	What is the focus of research?
AMD Wet	Age related macular degeneration cannot be cured. The exact causes are unknown but the condition develops as the eye ages. If wet AMD is diagnosed early, treatment may help slow progression and prevent further sight loss, although treatment is not effective for everyone.	<ol style="list-style-type: none"> <li>1. Anti-VEGF medication may help stop growth of new blood vessels. The ophthalmologist injects these medications directly into the eye.</li> <li>2. Photo dynamic therapy—laser treatment using a light-sensitive drug injected into the arm. The drug travels to the eye where it is activated by a laser beam, shutting down the abnormal blood vessels.</li> </ol>	<ol style="list-style-type: none"> <li>1. Improving Anti-VEGF drugs and their delivery (wet only).</li> <li>2. Developing new drug therapies.</li> <li>3. Developing stem cell replacement therapies.</li> <li>4. Developing retinal implants.</li> <li>5. Developing rehabilitation strategies.</li> </ol>
AMD Dry	Dry AMD cannot be cured. The exact causes of dry AMD are unknown, but the condition develops as the eye ages.	There is currently no treatment for dry AMD. The disease may progress slowly. However for a significant number it will progress faster and develop into wet AMD.	
Cataract	Cataracts cannot be cured. They develop as we age. Most people over the age of 65 have some changes in their lens and most of us will develop a cataract in time.	The only effective treatment for cataracts is surgery to remove the cloudy lens and replace it with an artificial lens implant.	<ol style="list-style-type: none"> <li>1. Preventing the development of cataracts.</li> <li>2. Improving surgery.</li> <li>3. Preventing posterior capsular opacification (post-surgery clouding of the lens).</li> </ol>
Diabetic retinopathy	Diabetic retinopathy cannot be cured. However, it has been shown that very tight control of blood sugars, blood pressure and stopping smoking can substantially delay the progress of the disease, and also contribute to a better outcome after laser treatment.	<ol style="list-style-type: none"> <li>1. Early-stage retinopathy may not need to be treated.</li> <li>2. Photo dynamic therapy—laser treatment can stop the progression of the disease particularly when it has reached the proliferative stage.</li> <li>3. Anti-VEGF medication may help stop the growth of new blood vessels.</li> </ol>	<ol style="list-style-type: none"> <li>1. Using stem cells to repair damaged blood vessels in the eye.</li> <li>2. Improving drug therapies.</li> </ol>
Glaucoma	Diagnosis of glaucoma is often not early enough for treatment to be successful.	<ol style="list-style-type: none"> <li>1. Treatments aim to reduce further damage and lower the eye pressure using eye drops or laser treatment.</li> <li>2. Surgery, with the most common procedure being a trabeculectomy—however, the use of a stent or tube implant is becoming a little more frequent, although can not yet be described as common.</li> </ol>	<ol style="list-style-type: none"> <li>1. Developing better surgical techniques.</li> <li>2. Improving delivery mechanisms for eye drops.</li> <li>3. Developing drug therapies to protect the optic nerve from damage.</li> <li>4. Developing stem cell treatment to protect, repair and regenerate the optic nerve.</li> </ol>

### iii. Eye research is underfunded

#### Box 19: The UK funding landscape

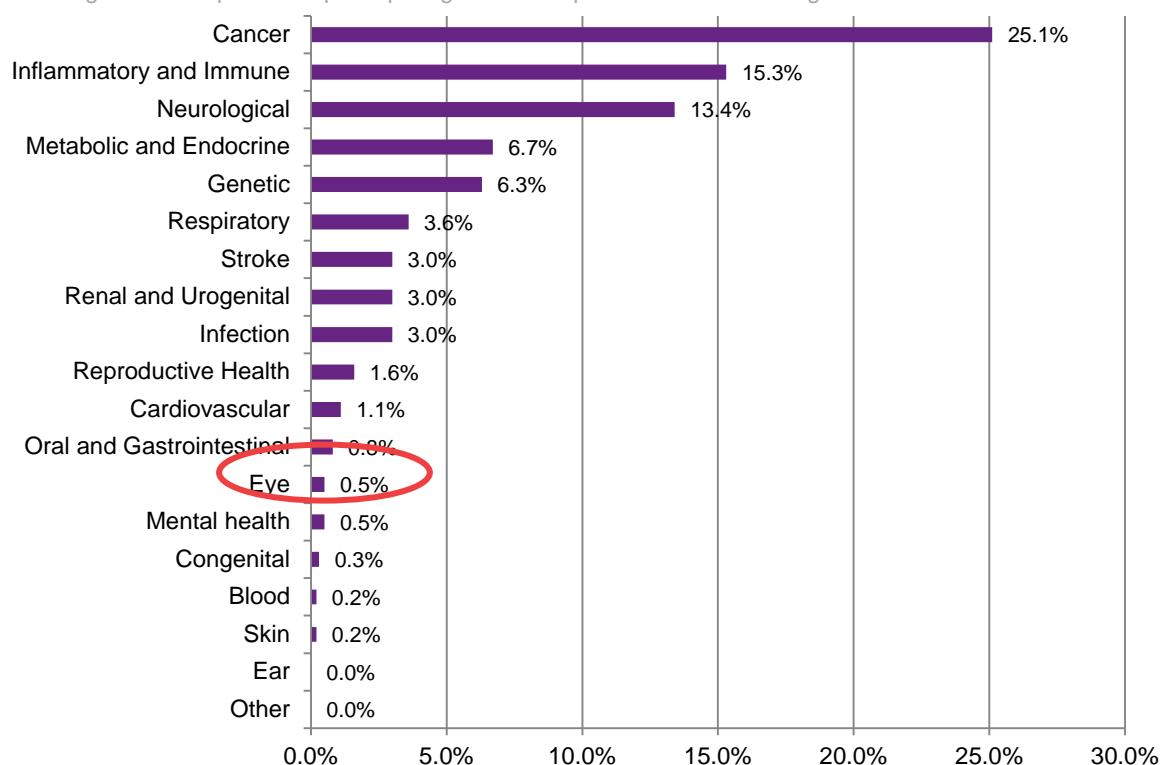
There is a considerable mismatch between the public's view of sight loss, as the disability we fear most, and the funding landscape.

The sector receives £30m of funding annually for eye research, which corresponds to £83 per year for each of the 360,000 people registered as blind or partially sighted.

Eye research receives a disproportionately low amount of research spend in the UK. Several pieces of evidence suggest that funding for eye research is low compared to other diseases.

- Expenditure on problems with vision accounted for 2% of the Department of Health Programme Budget National Level Expenditure in 2010/2011.<sup>123</sup> However, eye research only received 0.9% of the NIHR (National Institute for Health Research) research spend (2011/12), and 2.2% of the Medical Research Council combined eye and ear spend (2012/13).
- Eye research accounted for only 0.5% of the total spend on medical research within small and medium sized AMRC member charities in 2004/05, the most recent period for which data is available.<sup>124</sup> This excludes the two largest funders—Cancer Research UK and the British Heart Foundation. If these were included the percentage would slip further (see *Figure 14*).

Figure 14: Proportion of participating charities' spend in all health categories



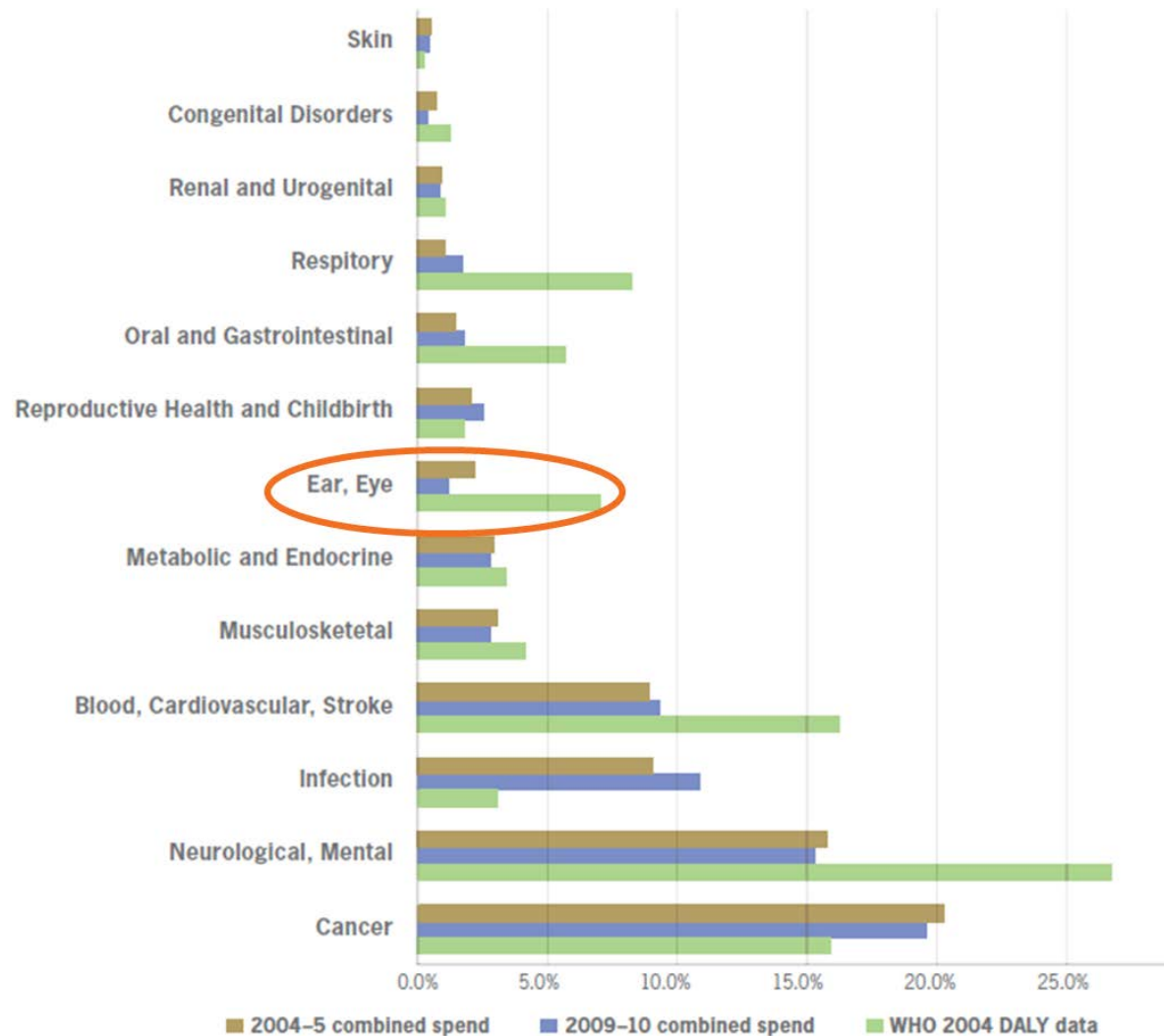
Source: UK Clinical Research Collaboration (2007) *From Donation to Innovation. An analysis of health research funded by medium and smaller sized medical research charities*. Association of Medical Research Charities.

<sup>123</sup> Department of Health website of 3 May 2012. *Programme budgeting tools and data*. Accessed via the National Archives.

<sup>124</sup> UKCRC (2007) *From Donation to Innovation. An analysis of health research funded by medium and smaller sized medical research charities*. AMRC.

- The *UK Health Research Analysis 2009/10* report,<sup>125</sup> which includes the largest government and charity organisations that fund research relevant to health, showed that the combined spend on ear and eye research has fallen as a percentage between 2004/05 and 2009/10. Within this figure, the spend on eye research has increased, whilst the spend on ear research has fallen. However, when looked at with reference to the World Health Organisation 2004 Disability Adjusted Life Years (DALY) data,<sup>126</sup> which measures the burden of disease, there is a clear discrepancy (see *Figure 15*).

Figure 15: Proportion of combined spend on health specific categories with WHO DALY rates



Source: UK Clinical Research Collaboration (2012) *UK Health Research Analysis 2009/10*. UKCRC.

125 UKCRC. (2012) *UK Health Research Analysis 2009/2010*. UK Clinical Research Collaboration.

126 DALYs are a measure of the life years lost to premature mortality and years lived with a disability adjusted for severity.

The total annual funding of eye research (excluding that spent by industry) is estimated to be around £30m. Charities account for about 20% of this figure, the Wellcome Trust for a further 20%, and government for the remainder. Among charities, the largest funder is the eye research charity Fight for Sight, which spends just under £4m per annum.

#### **Box 20: Fight for Sight**

Fight for Sight is the largest charitable funder of medical research in the eye sector. During 2011/12 it awarded new grants totalling £3.6m. Grants are restricted to teams attached to UK institutions undertaking work in the UK or overseas. Grants are selected following open competition and external peer review. The charity is currently funding research at 28 different universities and hospitals.

Fight for Sight aims to grow its grants, and administers joint research awards with nine other charities.

Its major grants include three year PhD studentships (£100,000), project grants (£170,000), clinical fellowships (£190,000) and Early Career Investigator Awards (£200,000).

Charitable funding for eye research, excluding that from the Wellcome Trust, is low: an estimated £6m<sup>128</sup> for a sector with over 600 registered charities, and where the income of the two largest (RNIB and Guide Dogs) totals almost £170m. Almost all of the charities in the sector do not fund medical research, focussing instead on providing services, support and information.

#### **Box 21: Other charities funding medical research**

RNIB carries out research related to the prevention of sight loss, and social research. For example its current Optimum VI project is the first national research study of its kind into the early development of babies and young children with a visual impairment.<sup>127</sup>

Guide Dogs spends £400,000 each year on research, concentrating on four areas: canine, ophthalmic, psycho-social and applied technology research. The research is designed to provide a sound evidence base for Guide Dogs' policies, operational procedures and campaigns, consistent with its mission.

The Thomas Pocklington Trust spends upwards of £400,000 each year on social and public health research initiatives to identify practical ways to improve the lives of people with sight loss.

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<sup>127</sup> RNIB website. *Research in progress*. Accessed October 2013.

<sup>128</sup> Research funders include Fight for Sight, British Retinitis Pigmentosa Society, National Eye Research Centre, British Council for Prevention of Blindness and the Macular Society.

#### iv. Eye research infrastructure is not prioritised

Eye research is not only underfunded: it is not prioritised. By this we mean that the infrastructure in place to support research into other diseases is not always present for eye disease. The research infrastructure needs to be improved.

- There is no eye research data repository, which means there is a lack of reliable data in the sector. The separation between primary and secondary care may well contribute to this. There are two notable data collection initiatives, both funded within the sector. Moorfields/UCL is developing *Open Eyes*, a collaborative, open source project to facilitate clinicians sharing electronic patient records. The data in these records will in due course provide a useful dataset for research, but that is not intended to be its primary function. The British Ophthalmological Surveillance Unit (BOSU) supports the logging and monitoring of uncommon eye conditions using data gathered by ophthalmologists, and is funded by Fight for Sight and The Royal College of Ophthalmologists.
- There is an Ophthalmology Speciality Group in the Comprehensive Clinical Research Network (CCRN), which is part of the NIHR Clinical Research Network. However, it is not funded to the same degree as those conditions that have specific clinical research networks to co-ordinate clinical trials.<sup>129</sup>
- There is no clinical lead for eye health supported by the government, in a role similar to that of Chief Medical Officer or Chief Dental Officer. RNIB has repeatedly called for a National Clinical Director for eye care based in the NHS who could act as a champion for eye health.<sup>130</sup>

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<sup>129</sup> These include those for cancer, stroke, mental health, diabetes, medicines for children and dementias and neurodegenerative diseases.

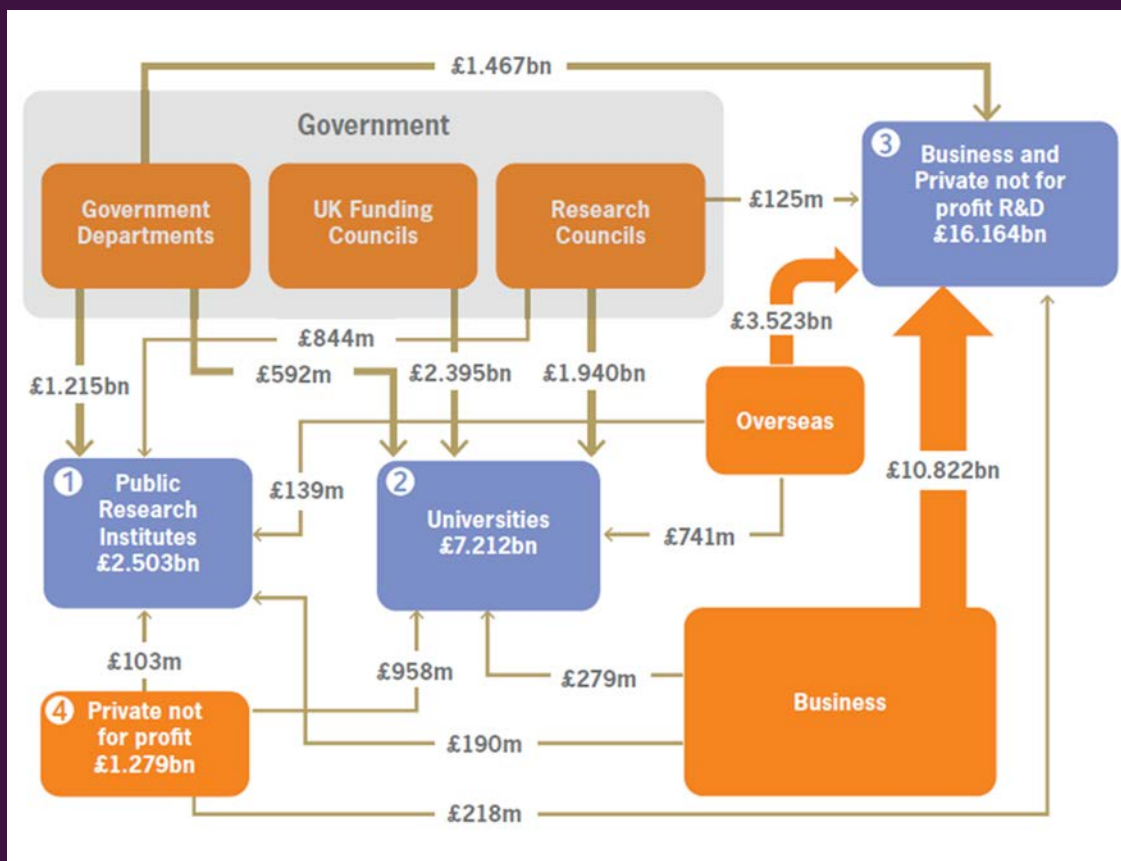
<sup>130</sup> RNIB (2013) *Surgery deferred. Sight denied. Variation in cataract service provision across England*. RNIB.

**Box 22: How is research funded in the UK?**

Research in the UK is funded by a range of organisations. The largest of these are listed below, and Figure 16 shows the flows between funders for 2009/10.

- **Government**, through a number of mechanisms: direct funding to universities via the Higher Education Funding Councils; the seven major research councils, including the Medical Research Council; and the National Institute for Health Research (NIHR) which includes funding for Biomedical Research Centres (BMRCs).
- **The Wellcome Trust**, the largest independent charity in the UK.
- **Other charities**, the largest being Cancer Research UK and the British Heart Foundation.
- **Industry**, primarily pharmaceutical.
- **The Charity Research Support Fund (CRSF)** is a top-up funding stream to support universities to cover the costs associated with charity-funded research that are not covered by research awards from charities. The awards are only for grants that are awarded under open competition and are peer reviewed.

Figure 16: UK expenditure on health related research and development 2009/10



Source: UK Clinical Research Collaboration (2012) *UK Health Research Analysis 2009/10*. UKCRC.

## 2. What could make a difference in the sector?

There are three broad changes we believe could be made to improve the state of the eye research sector:

- i. the development of a strong sector profile and a united voice in support of medical research;
- ii. an effort to ensure more of the right research takes place in the right way, and money is well spent; and
- iii. structuring medical research to ensure maximum impact.

### i. Developing a sector voice in support of medical research

#### Support for research should be cross-sector.

As the need for treatments and cures becomes more urgent, the sector is increasingly coming together to identify priorities and talk with one voice, achieving higher levels of cross-sector collaboration than it has in the past. But this effort is not filtering through to the public, who lack knowledge of some major eye diseases and don't always understand the need for eye research. At a recent roundtable hosted by NPC focussing on sight loss and issues for older people, there was broad agreement that a lot of high-quality information is available on eye health and eye disease. However, it is not getting into the hands of the right people at the right time.

Many of those we interviewed when writing this report felt that the profile of eye medical research, although rising, has further to go in order to create the necessary sense of urgency. The refreshed UK Vision Strategy 2013-2018 includes reference to medical research for the first time, as one of the six priority actions for outcome one (*'everyone in the UK looks after their eyes and their sight'*).<sup>131</sup>

*'To promote investment in further research to reduce sight loss through development of interventions for conditions that are currently untreatable and also to build an evidence base for effective rehabilitation and support services.'*

UK Vision Strategy 2013-2018

The larger charities in the sector, which have a high profile with the public, are not focussed on funding medical research. This presents an enormous challenge for charities that do fund research. Figure 17 shows the size of a number of visual impairment charities; the main medical research funders are shown in bold.

Figure 17: Visual impairment charities by size

Scale	Representative charities
<b>Large Income £50m+</b>	National: RNIB (including Action for Blind People); Sense; Guide Dogs International: Sightsavers
<b>Medium Income £10-50m</b>	Blind Veterans, Royal Blind Society, Seeability
<b>Income £5-10m</b>	National: Thomas Pocklington Trust, RLSBP, WESC Foundation, Royal National College for the Blind

<sup>131</sup>UK Vision Strategy (2013) *UK Vision Strategy 2013 – 2018. Setting the direction for eye health and sight loss services*. UK Vision Strategy.

	International: Christian Blind Mission
<b>Income £3-5m</b>	Catholic Blind Institute, Deafblind UK, Clarity, <b>Fight for Sight</b> International: Orbis
<b>Income less than £3m</b>	Visionary (a membership organisation for local sight loss charities) <b>The Macular Society, British Retinitis Pigmentosa Society, International Glaucoma Association</b> (all specialists with small research budgets)

Any public awareness campaign would benefit from the support and authority of the larger charities in the sector. A major drive to increase charitable donations for medical research would struggle without the main players committing to the need for medical research. This does not mean, however, that the main players need to engage directly in medical research.

A number of different models have been developed to both provide care and fund research into specific conditions. For example, Macmillan and Cancer Research UK are the two dominant charities in the cancer sector, specialising in care and research respectively. In contrast, Parkinson’s UK and the Multiple Sclerosis Society both combine support and research. NPC does not advocate either model in particular, but in both cases, the charities rely on brand awareness and scale. In the case of sight loss, the research charities are small and would benefit from pooling resources to create economies of scale for example in peer review and grant administration. In terms of brand awareness, sight loss research charities do not have the same recognition as the large charities in the sector: RNIB and Guide Dogs. The largest, Fight for Sight, was formerly the British Eye Research Foundation, and has only started to build its brand as a national research charity in the past seven years.

Bringing medical research into the mainstream for the sector remains a challenge.

## ii. Ensuring maximum impact: the right research in the right way

Clearly this is a highly subjective issue and opinions will differ as to which is the ‘right’ research and what is the ‘right way’ to do it—not to mention other barriers that stand in the way. Is the right research that which meets the greatest need? Or do you fund the disease that causes the greatest number of registrations of blindness and partial sight? Or do you focus on rare diseases that affect a small number of people? And how do you focus funding on the right part of research process?

Clearly, identifying and funding the right research is challenging. This section discusses a number of actions to help the sector pursue the right research in the right way:

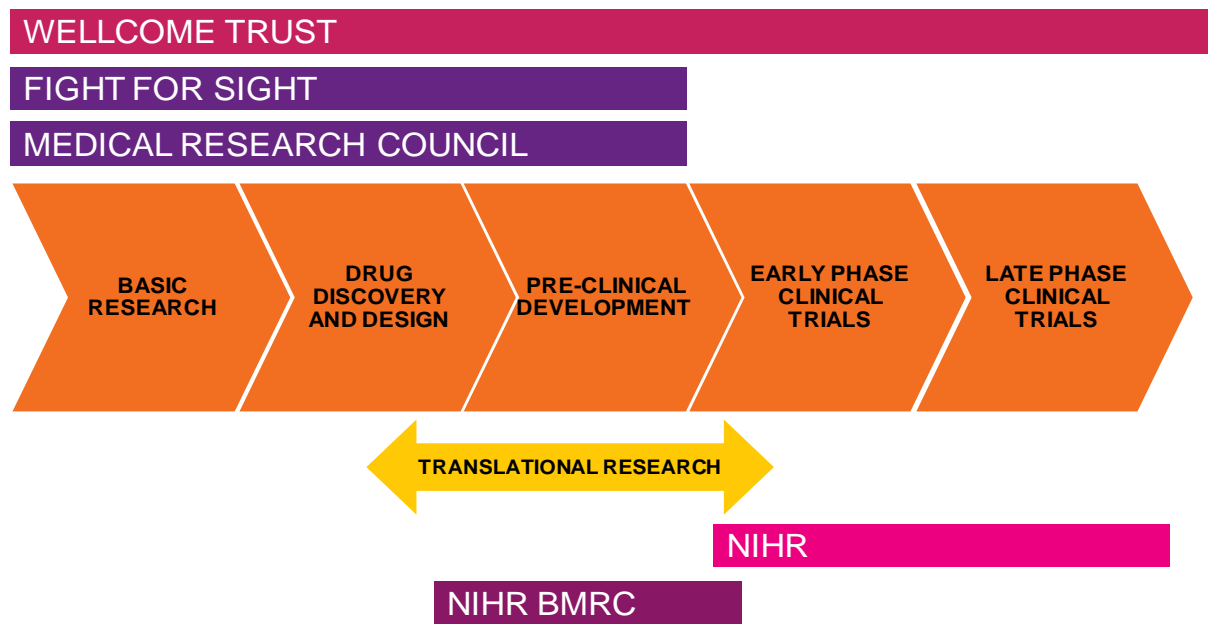
- prioritising neglected parts of the research chain;
- public patient involvement; and
- new business models for research.

### Prioritising neglected parts of research chain

The lack of funding for pre-clinical development and translational research is still a problem in eye research. Within research, funders focus on different parts of the research chain. This chain is illustrated in *Figure 18* below, with the chevrons showing the stages of research and the profile of the major funders, excluding industry.



Figure 18: Research stages and the major funders



Source: Fight for Sight

Debate continues across the research sector as to whether the ‘right’ research is taking place to move medical knowledge along at the speed required. Many are concerned about the wide gap between researchers and the patients who need their discoveries. To try to bridge this gap, the sector globally has begun to focus more on translational research, and on investing in training, research and infrastructure.

In the UK, this shift in focus led to the establishment of the National Institute for Health Research (NIHR) in 2006, dedicated to translational research, and a year later, the establishment of the Moorfields Eye Hospital/UCL Institute of Ophthalmology National Institute for Health Research Biomedical Research Centre (BMRC), which is a partnership between Moorfields Eye Hospital NHS Foundation Trust and the UCL Institute of Ophthalmology. As part of the NIHR, the BMRC’s job is to take advances in basic medical research from the laboratory to the clinic, enabling patients to benefit more quickly from new scientific breakthroughs.

The Wellcome Trust funds across the spectrum, from basic research though to late phase clinical trials. The Medical Research Council principally focusses on basic research, along with Fight for Sight. The NIHR and Wellcome Trust support clinical trials, as does industry, but despite the NIHR BMRC funding at Moorfields there is still a lack of funding for the pre-clinical development or translational research necessary ahead of clinical trials.

Translating a basic discovery into a biological or chemical compound ready to be tested on humans is a complex, time-consuming and iterative process. Companies or funders often want ‘proof of concept’ before taking a drug forward, and many are investing later in research, or being more conservative in their funding. The ‘valley of death’ is the industry term for the gap between a promising discovery and the point at which a funder will pick up the drug and move it forward. Medical ‘action tank’ *Faster Cures* identifies four challenges to moving research through the ‘valley of death’:<sup>132</sup>

- lack of funding for translational research;
- lack of technical expertise among researchers about how to move discoveries through the pipeline;

<sup>132</sup> *Faster Cures* (2010) *Crossing over the valley of death: Translational research*. *Faster Cures*.

- lack of incentives for scientists to move their discoveries forward; and
- high risk of failure, which makes companies risk averse.

The valley of death remains an issue in the sector, and not enough of the ‘right’ research is occurring.

### Public patient involvement

Public patient involvement can help to identify the ‘right’ research.

Charities are adopting different approaches to public patient involvement. Some are asking members to determine priorities, or holding public consultations (for example, Asthma UK and Kidney Research UK); others are involving lay panels in assessing grant applications (for example, Alzheimer’s Research UK).

Many organisations across the eye sector have come together to set joint priorities, through the Sight Loss and Vision Priority Setting Partnership (PSP).<sup>133</sup> This exercise, facilitated by the James Lind Alliance, brought patients, carers and clinicians together to identify and prioritise for research the treatment uncertainties that they agreed are the most important.

*‘The Priority Setting Partnership has been incredibly important as it has given the public a loud voice. They are telling us that eye and vision research is very important to them, and they have also clearly expressed their priorities. Researchers need to know these priorities, embrace and use them to maximise their case for funding.’*

**Professor Sir Peng Tee Khaw, Director of the NIHR Biomedical Research Centre, Moorfields Eye Hospital and UCL Institute of Ophthalmology**

The full report on the consultation was published in October 2013, and lists the top ten priority research questions for twelve categories of eye disease or condition, including glaucoma, AMD and cataracts.

#### **Box 23: The Tommy Salisbury Choroideremia Fund at Fight for Sight**

In 2005, Fight for Sight started working with the Salisbury family to fund research into choroideremia, establishing the Tommy Salisbury Fund at Fight for Sight. The fund raised over £300,000 to support research undertaken by Professor Miguel Seabra at Imperial College London into a potential gene therapy trial. The money from the fund enabled the research at Imperial to go ahead, which has since led to the first clinical trial for choroideremia being undertaken at the University of Oxford, funded by the NIHR and the Wellcome Trust.

The clinical trial would not have been possible without the resources provided by the fund. This example illustrates the power that individuals can have in influencing the course of research.

<sup>133</sup> Sight Loss and Vision Priority Setting Partnership (2013) *Setting Priorities for Eye Research*. The James Lind Alliance.

**Box 24: Next steps for the Sight Loss and Vision Priority Setting Partnership<sup>134</sup>**

- For existing research funders—government, charities, and the private sector—to use these priorities to support funding decisions.
- For existing funders to increase investment in eye research, and for more organisations to commit resources to address these priorities.
- For researchers to state which priorities their research aims to address when applying for grants. In this way, researchers can demonstrate to funders why their research is so important to the people affected.
- To use the priority lists to help ensure that funders work together to address as many of the priorities as possible—the first time that such a mapping exercise can be contemplated in the sector.

Although a major achievement, some caveats to the PSP exercise were raised:

- Initial ranking priorities may be different between different stakeholders, for example doctors and patients may disagree.
- Following the PSP research priorities may not always be conducive to sustained pursuit of an elusive answer.
- Some specialty areas had 'top heavy' responses from specific patient groups whose disease would be considered as rare.
- Most social research, for example qualitative studies, was excluded.
- Responses from basic scientists regarding basic science research were excluded.

Following a priority setting exercise such as the one above, the 'right' research can be identified and driven by the priorities of those with the disease. This kind of public patient involvement is seen by some in the sector as an opportunity not just to inform existing funders, but to engage new funders in eye research by showing them that it is focussed in areas that patients and clinicians have identified as a priority. This approach to directing funds has implications for reactive funders that have historically been researcher-led, where the direction of research grants is primarily driven by the quality of research applications (provided they fit the overarching strategy of the funder).

### **New business models for research**

New business models are being developed to accelerate research.

Charity funders can use their unique position to drive research forward in under-researched areas. Charities are not constrained in the same way as academic institutions, and do not seek to make a return for investors in the way that industry does. They could therefore make riskier investments to move research along.

Faster Cures<sup>135</sup> in the US has taken this process one step further, and is promoting a new business model aimed at moving research along more quickly. Directed, targeted research sits as the heart of the model, which requires organisations to become experts and raise capital to push projects into trials.

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134 Michele Acton of Fight for Sight speaking at the launch of *Setting Priorities for Eye Research Final Report*, October 2013.

135 Faster Cures website. Accessed October 2013.

### iii. Structuring medical research to achieve maximum impact

NPC found that there remain significant bureaucratic barriers to medical research, particularly around clinical trials, which frustrate researchers. These issues are common to the whole research sector, and are outside the scope of this report.

The difficulty of evaluation and measurement of the impact of medical research is also common to the sector and an area that interested funders could research further.

However, our research found several issues specific to the eye sector where action could be taken to make a difference:

- bolstering the research workforce;
- developing a more connected and collegiate research network; and
- building collaboration and strategic alliance.

#### **Bolstering the research workforce**

Involving more clinicians in research, with their specialist understanding of clinical issues, could speed up translational work. However, the demand for service delivery in ophthalmology is so overwhelming that consultants do not have time to conduct research. Academic Clinical fellowship and Clinical lectureship programmes are designed with this in mind, and aim to protect a proportion of a clinician's time for research.

Training the next generation of researchers is vital, but it is difficult to keep researchers in research. Although there is funding available for PhDs and post-doctorates, progression for researchers early in their career is limited and can lead to a high dropout rate. Professor Waterman, of the School of Nursing, Midwifery and Social Work at the University of Manchester, puts the shortage of trained researchers in nursing and ophthalmology down to the difficulty of getting funding for PhD studentships, and the NHS priority of clinical work over research. Professor Andrew Dick, Professor of Ophthalmology at Bristol Eye Hospital, suggested a culture change was needed in the NHS to enable more doctors to get involved in research. Moreover, he thought it likely that their patients would be happy to engage.

Reducing the sector's dependence on a small group of researchers is necessary. Ophthalmology is small, and needs more chairs or professorships to expand the pool of researchers.

#### **Developing a more connected and collegiate research network**

Moorfields/UCL dominates in size, and should use its position to make links with other research centres, as it has done with the University of Bristol. Fight for Sight funds 28 institutions in the UK, and the sector would benefit from recognising and utilising the strengths of other areas of excellence.

It was mentioned that the dominance of Moorfields/UCL in NIHR funding for translational research could disadvantage researchers outside this niche. In our research, we heard that the sector would benefit from a mechanism to ensure funding was spread across research centres in the UK.

The sector needs to address the distribution of funding, and also consider how to link professionals more closely together. The eye sector does not have such well-developed research networks as other disease areas. The ophthalmology research network was politely termed 'not very active' by several people we spoke to during our research.

Two other improvements in infrastructure were suggested that would help connect researchers across the country: first, better access to eye data with the development of a national eye data repository or something

similar; and second, improved access to retinal tissue. There is currently no incentive for eye banks to provide tissue for research as their primary purpose is corneal transplantation, which means access is unpredictable.

### **Building collaboration and strategic alliances**

Professor Sir Peng Tee Khaw, Director of the NIHR Biomedical Research Centre at Moorfields Eye Hospital and UCL Institute of Ophthalmology cited the need for increased collaboration across the sector. This requires researchers to show that they *'understand the bigger picture and are prepared to talk to industry'*.

Moorfields/UCL has increased collaboration with industry by over 400% in five years, with initiatives such as the GlaxoSmithKline partnership and Pfizer's support of stem cell research for AMD. In 2008, The London Project teamed up with Pfizer to help move the project into the clinic so as to determine whether this cell replacement therapy was safe and if it led to an increase in vision in patients. These major partnerships help keep industrial funding and ensure an industry presence in the UK research sector, which fits the government's growth agenda and is a major driver behind preserving the UK research budget.

The sector would benefit from leveraging its capacity by creating strategic alliances, with researchers internationally and with industry—for example, the UNITE Human Ocular Immunology Consortium between the NIHR BMRC at Moorfields and UCL Institute of Ophthalmology, and the University of Bristol/University of Bristol Hospitals with the National Eye Institute in America, launched in May 2013. The consortium was formed to encourage the transfer of technologies, scholars and bio-materials for immune mediated eye diseases such as uveitis, AMD and diabetic retinopathy.

#### **Box 25: The National Eye Institute**

The National Eye Institute was established in the USA in 1968. Its mission is to conduct and support research that helps prevent and treat eye diseases and other disorders of vision. It is federally-funded, and makes a significant contribution to the profile and funding of ophthalmology research in the US.

### 3. What are the funding opportunities?

Although there is general agreement across the research community that medical research is underfunded, we believe that the research community could better articulate its needs. The sector needs to be able to make a strong case for research funding: it must be able to show that eye research has been underfunded in the past, and most importantly to explain why this must change going forward. Arguments for investment in eye research must stress the tsunami of need that is approaching, and the need to take advantage of the exciting opportunities.

Part of this reticence may be due to the relatively small size of the research community compared to other disease groups. Some may of course be due to having never been asked to make the case for funding in this way! But researchers and fundraisers alike should be able to persuasively convey the concrete and practical needs of the sector—beyond simply more money. The results from the Priority Setting Partnership should help to develop this message.

NPC has identified several areas that a funder interested in medical research might want to consider, which we outline below.

#### Research priorities: mapping and gap analysis

As a result of the PSP, the sector knows what patient and eye health professionals want research to address. To maximise the benefits of this information, work is needed to map research commissioned against the priorities set, to provide patients and funders with relevant and current information about the state of research in the sector. This information would increase knowledge about eye research and identify any gaps in research commissioned.

The project, depending on scale, could create an online facility to map research commissioned against priorities set. This would serve several purposes:

- It could provide an information source for patients to learn about research being undertaken by different funders to address their particular eye disease or condition.
- It could enable the identification of areas of priority to patients and eye health professionals that are not attracting funding—known as gap analysis.
- It could provide information which could be used to lobby funders for additional research funding.
- It could take the information consolidated into the facility to provide the basis for talks at patient days.

Cost: up to £150,000, depending upon scope.

#### Capacity building

Eye research is a small but internationally recognised sector. We identified several areas which, if invested in, could further leverage this expertise and increase the capacity in the sector.

##### Workforce

Funders can help build research capacity through providing funding for clinical fellowships and clinical research training.

Cost: £200,000 over three years.

Funders can train the next generation of researchers by providing grants for PhD studentships. Fight for Sight funds three-year PhD studentships to the value of £100,000.

Cost: £100,000 over three years.

Further funding is also needed for researchers with more than two years post-doctorate experience, where there is currently very little available. These funders are therefore dropping out of research, a trend that jeopardises the future of the sector.

Funders can reduce the dependency of the sector on a relatively small number of researchers by funding chairs or professorships.

Cost: £120,000-£160,000 each year.

### **Revenue grants**

The Priority Setting Partnership will enable funders to better target their donations to fund the areas that patients want. Within these priorities, the funding gap that has been identified is for the pre-clinical development or translational research necessary ahead of clinical trials.

Cost: £170,000 upwards for three-year project grants.

### **Grant funding research charities**

The largest charity funding eye research, Fight for Sight, has to turn down five out of six applications. The Macular Society, which funds medical research into AMD, has said the number of applications it receives has doubled in 2012/13, indicating a need for more funding. Universities receiving a grant from a charity that undertakes peer review and open competition will benefit from the Charity Research Support Fund (CRSF) uplift.

### **Grants management system**

No eye medical research charity has a sophisticated grants management system. Research charities in other sectors benefit from such a system which can provide end-to-end management and reduce administration time and costs. Researchers also benefit as such systems can allow them to set up their own online account which can be edited and updated, making it easier to apply for grants. Given the resources required to run a grants programme, it is sensible that one charity leads on developing a suitable system.

Cost: initial system cost £80,000 for installation; annual maintenance £7,000-£14,000.

### **Infrastructure investment**

The eye research sector does not have the research infrastructure of other sectors. Improved infrastructure would enable researchers to leverage their research more effectively, with the aim of pushing promising discoveries through the research spectrum to clinical trial more quickly. Two areas mentioned in the course of our research were:

- Development of a national eye data repository to improve access to data for researchers. The lack of access to such data at present is seen as a barrier to effectively providing evidence for research awards.
- Development of a more vibrant clinical research network, through research to understand how specialist clinical research networks in other disease areas have provided support for projects and increased collaboration.

### **Capital investment**

Ongoing capital investment in research equipment is required to support researchers in their work and enable them to stay at the cutting edge of research.

Current Fight for Sight grant applications include funding for the purchase of small pieces of equipment such as a luminometer<sup>136</sup> (cost £5,016) and a Quantum WARP Light device<sup>137</sup> (cost £3,000).

The Moorfields Eye Charity spent £200,000 on equipment in 2011/12, purchasing specialist equipment for the Research Centre for Eyes and Vision, including a Topcon retinal camera<sup>138</sup> and the Eyelink 1000 eye tracker.<sup>139</sup>

Cost: variable.

### Research applications and pilot studies

The research councils have identified that a lack of sufficient evidence and data is often a barrier for researchers applying for larger grants to take their research to the next level. Funders can fund pilot studies to gather the evidence needed to provide the basis to attract further funding for large scale clinical trials supported by others. Rosetrees Trust provides seed corn funding to cutting edge projects across medical research, which funders like the Wellcome Trust and the MRC would want to take forwards to clinical benefit.

Cost: £15,000 upwards.

### Collaboration and alliances

There is an emerging need for investment in the development of strategic alliances and cross-sector collaboration to access larger funding opportunities such as EU funding.

Cost: variable.

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136A luminometer is an instrument used to measure light intensity and optical properties that appear on different surfaces.

137The Quatum WARP 75 is a LED (light emitting diode) unit, intended for the treatment of chronic pain by emitting energy in the near-infrared spectrum.

138 A Topcon retinal camera is a microscope attached to a camera providing which detects and monitors degenerative eye diseases affecting the back of the eye.

139 The Eyelink 1000 eye tracker measures the point of gaze and movement of the eye while allowing the patient to move their head.



## Medical research: Conclusions

- Medical research in the eye sector is underfunded and not prioritised by some key stakeholders—including government, charities and the public. The sector must continue to raise its profile and convey the sense of urgency around sight loss, in order to get the issue on the agenda and raise more funds for eye medical research. Medical knowledge is advancing rapidly, but there is still a long way to go: there are many different eye diseases for which the cause is unknown; there are some for which there is no treatment; and the 'holy grail' of reversing sight loss is still a distant goal.
- The right kind of research is not being funded on a sufficient scale. More translational research is needed to bring medical advances from the lab to the clinic more quickly. More funding for pilot studies would provide the evidence needed to allow further investment in new treatments.
- The sector has made a concerted effort to understand and address patient priorities: the next step is to integrate these into research programmes. By identifying patient priorities the sector can direct funds where they are most needed. However, the sector should beware of neglecting research where the translational benefits are further off, such as basic science.
- There are a number of barriers to scaling up research that are particular to the visual impairment sector, which has a less developed research infrastructure than some other diseases. These barriers can be addressed by investing in the research workforce and infrastructure and by leveraging knowledge.

# CONCLUSION

People with sight loss need not lose out in life, and with the right support can play a full and active part in society. But, as we have discussed in this report, at present this support is often over-stretched. Raising awareness, together with investment in research and technology could help overcome many of the negatives associated with visual impairment.

Now is the time to act: increasing need, in part due to an ageing population, is driving eye health up the government agenda; advances in science and technology continue to produce new approaches to prevention, treatment and adaptation to sight loss; and there is already momentum in the sector for collaboration and new ways of working.

We have explored the landscape for older people with visual impairments, and discussed the need for investment and development of eye medical research. Both areas are closely linked, and particular themes reappear.

## Raising awareness of eye health

Although we learnt that sight loss is the disability we fear most, this doesn't seem to have translated into proactive engagement by the public with eye health. Many people have trouble making the leap from a fear of blindness to taking better care of their eyes. 76% of people would rather lose a limb than lose their sight—yet less than half of those over 60 have an annual sight test. We take our vision for granted: we don't look after it as we do other parts of our body; we don't seek medical advice as soon as our eyesight changes. A successful public health campaign could make people—and especially older people—much more aware of the health of their vision, and encourage them to look after their eyes. Charities have a key role to play here to talk directly to the public and to lobby for government action.

That sight is low priority for the public affects medical research too. Whilst other diseases attract huge levels of support and donations, and benefit from high public profiles, research into sight loss does not have the same pull. We need to create a sense of urgency around sight loss. The seriousness of its impact on individual lives; the growing scale of the problem—particularly in an ageing population; and the wider costs society could face if we neglect the issue need to be understood by public and policymaker alike. Emphasising the many exciting opportunities for treatment, prevention and adaptation offered by new technology, and the gateways this opens up for dealing with visual impairment, will help to engage funders and policymakers.

Perhaps the most important conclusion to draw from this report is that many of the problems faced by those with sight loss are needless. Early diagnosis can stop many eye diseases or conditions developing further—better integration between health and social care and the visual impairment sector could help spot the symptoms of sight loss before it becomes irreversible. If the loss of sight cannot be stopped, early diagnosis allows sufficient time to help a person adapt to their deteriorating vision, and gain the confidence in new ways of doing things that can enable them to maintain a full life once their vision starts to fade. Practical adaptations to living conditions and public spaces can prevent them becoming off-limits to those with poor sight. Investment in medical research could lead to better treatment for conditions affecting the sight, or even the holy grail of the ability to restore lost vision.

## Charities can bring people together to champion eye health

Across both areas of our research, the case for more collaboration and working across charitable, public and commercial sectors, is compelling. Although partnerships are not always easy, in an area with as many different

stakeholders as eye care, working together can create change. Charities are uniquely placed as an independent actor in the middle of the sector to convene organisations around a clear goal. VISION 2020 (UK) Ltd's *Adult sight pathway* is a positive development, setting out the journey through health and social care services to help ensure smooth transitions between different aspects of eye care. We hope to see it applied and used across medical, health and social care.

Charities also represent the voice of those with visual impairments, and can help organise and articulate patients' views about the care they receive and priorities for research or funding. An initiative such as the *Priority Setting Partnership* (PSP) is just one example of charities leading the way to help the sector understand the desires of those it exists to help. Charities can also form partnerships with commercial providers, both as funders of medical research and to raise awareness of eye health. Targeting companies with a reason to take an interest in eye health—national optician's chains, pharmacies, private healthcare, insurance companies—is one possible approach.

The sector must work together to raise eye health as an immediate priority. It has implications for us all. The fear that we have of losing our sight should be reflected in the care that we take of our eyes.

## TRANSFORMING THE CHARITY SECTOR

NPC (New Philanthropy Capital) occupies a unique position at the nexus between charities and funders, helping them achieve the greatest impact. We are driven by the values and mission of the charity sector, to which we bring the rigour, clarity and analysis needed to better achieve the outcomes we all seek. We also share the motivations and passion of funders, to which we bring our expertise, experience and track record of success.

**Increasing the impact of charities:** NPC exists to make charities and social enterprises more successful in achieving their missions. Through rigorous analysis, practical advice and innovative thinking, we make charities' money and energy go further, and help them to achieve the greatest impact.

**Increasing the impact of funders:** We share the passion funders have for helping charities and changing people's lives. We understand their motivations and their objectives, and we know that giving is more rewarding if it achieves the greatest impact it can.

**Strengthening the partnership between charities and funders:** Our mission is also to bring the two sides of the funding equation together, improving understanding and enhancing their combined impact.

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