

Chapter 1: Background information about sight loss

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Introduction

This chapter provides an introduction to sight loss. It looks at the varied methods employed to define and qualify ‘sight loss’ and emphasises that researchers must clarify their terms when recruiting participants and producing research outputs. The chapter also aims to demonstrate the range in type, severity and experience of sight loss. Researchers should be alert to the many ways that people experience and describe sight loss.

The following information does not relate to children under 18 years old. It should be used only in reference to adults.

Terminology

Common terminology used across the sight loss sector

Pocklington research reports often include this note:

‘In this publication, the terms “visually impaired people”, “blind and partially sighted people” and “people with sight loss” are used interchangeably’.

The background of these phrases is as follows:

- **Blind and partially sighted people.** These terms usually refer to the certification and registration process, and mean that someone's vision has deteriorated below a clinically defined level and cannot be corrected. The terms 'blind' and 'partially sighted' are now referred to as 'severely sight impaired' and 'sight impaired' in the certification and registration process, yet the previous labels are still commonly used in the sight loss sector.
- **'People with sight loss' and 'visually impaired people'.** Many people with a visual impairment do not meet certification and registration criteria. These phrases therefore capture a larger population, which includes people whose sight is deteriorating or who are waiting for treatment(s). They are used to describe a person who has an impairment of vision that cannot be fully corrected using glasses or lenses.
- **Low vision.** This includes, but is not limited to, those who are registered as sight impaired and severely sight impaired. The College of Optometrists and the Royal College of Ophthalmologists define low vision as an impairment of visual function that cannot be remedied by conventional spectacles, contact lenses or medical intervention and which causes restriction in everyday life.[1]

Self-identification

The variety of sight loss and differing experiences of sight loss mean that people will not identify themselves under one unifying label.

Some may simply refer to themselves as having 'poor eyesight', 'poor vision' or 'blindness'.

Those that are registered might say that they are 'registered blind' or 'registered partially sighted'. For some, the term 'blind' is misleading as people might suppose that it means someone has no vision at all, which is very rarely the case.

Some people may feel that the term 'sight loss' is not applicable to them. This may be because they were born with a visual impairment. Alternatively, they might feel that the word 'loss' has

1 The College of Optometrists and the Royal College of Ophthalmologists (2013), Commissioning better eye care: adults with low vision. www.college-optometrists.org/filemanager/root/site_assets/guidance/low_vision_guidance_25_11_13.pdf.

negative connotations and denies the skills that one develops as a result of growing up with, or adapting to, low vision.

Some may not like the term 'visually impaired' because they feel that it infers deficiency.

For these reasons, if you are talking to or about a particular person, you may wish to ask early on if they have a preferred term.

Less helpful terminology

- 'The blind' or 'the visually impaired'
- 'Suffering from sight loss' or 'suffering from a visual impairment'
- 'Effectively blind', 'fully blind' or 'legally blind'
- Patient. Not all people with sight loss are patients, so use this term only if it accurately describes the research participant, the research focus and their experience.
- Services users. Only describe participants this way if they are accessing services. The use of this term might suggest that they are using Pocklington services or services more generally.
- 'Had a stroke' – if the visual impairment is a result of a stroke, use the phrase 'survived a stroke' rather than 'had a stroke'.
- If an eye condition resulted from an injury or health condition like a stroke, it may be more helpful to use the term 'vision problems' rather than 'sight loss', which is a more accurate description of the wide variety of vision problems, such as eye movement and increased sensitivity to light.[2]

Causes of sight loss

Many different conditions have an impact on sight. The cause of sight loss could be genetic, the result of an accident, an illness or injury, or because of the ageing process of the eyes. Stroke, dementia and other neurological conditions can result in vision problems. Lifestyles can also have an impact.

Sight loss and severe sight loss can impair:

- **Visual acuity.** The sharpness or clarity of vision.
- **Visual fields.** The ability to detect objects to either side, above or below the direction in which someone looks.

2 RNIB, Stroke related eye conditions. www.rnib.org.uk/eye-health-eye-conditions-z-eye-conditions/stroke-related-eye-conditions [accessed July 2014].

• **Detection of colour and contrast.**

It should be noted that people are often unaware of the details of their sight loss, such as their visual acuity. Network 1000, a survey interviewing 1000 people registered blind or partially sighted, estimated that 23% of those interviewed did not know, or were unsure, of the name of their eye condition.[3] Someone might have more than one eye condition.

The five leading causes of sight loss in adults in the UK are refractive error, age-related macular degeneration, cataract, glaucoma and diabetic retinopathy:

- 16.7% of people have partial sight and blindness due to age-related macular degeneration
- 13.7% due to cataract
- 5.3% due to glaucoma
- 3.5% due to diabetic retinopathy
- 53.5% due to refractive error
- 7.4% due to other eye diseases[4]

The numbers of people with sight loss caused by other health conditions and injuries are unknown.

Age-related macular degeneration (AMD)

- **Area affected.** The macula is the central part of the retina that we use when looking directly at something and seeing things in fine detail, for example when reading, writing, driving and recognising faces.
- **Effect on vision.** It can make central vision distorted or blurry. It does not lead to a total loss of sight and is not painful. Over time, it may cause a blank patch in the centre of vision.

3 Douglas, G., Corcoran, C. and Pavey, S. (2006) Network 1000: Opinions and circumstances of visually impaired people in Great Britain. Visual Impairment Centre for Teaching and Research, University of Birmingham, pp.7-8.

www.vision2020uk.org.uk/core_files/Full%20Network%201000%20report%20-%20FINAL%20VERSION%20September%2006-MASTER.pdf [last accessed July 2014].

4 Access Economics (2009), Future sight loss UK 1: the economic impact of partial sight and blindness in the UK adult population. RNIB, London, p.37.

- **Cause.** Some cases of AMD are thought to be inherited. Some studies suggest that smoking and exposure to sunlight increase the risk of developing AMD.
- **Trends.** AMD is the most common cause of sight loss in the UK and the leading cause of sight loss among older people. It is most often seen in people over the age of 65, although it can develop in people who are in their 40s or 50s.
- **Treatment.** There are two types of AMD – wet and dry. Wet AMD tends to develop over years, whereas dry AMD causes blood vessels to grow into the macula and can develop very suddenly. A number of treatments are available for wet AMD and are more effective if administered at an early stage of the disease's development. Currently no treatment is available for dry AMD.

For more information on age-related macular degeneration, see:

RNIB, Age-related macular degeneration www.rnib.org.uk/eye-health-eye-conditions-z-eye-conditions/age-related-macular-degeneration-amd [last accessed July 2014].

Macular Society, Age-related macular degeneration www.macularsociety.org/about-macular-conditions/Age-related-macular-degeneration [last accessed July 2014].

Cataract

- **Area affected.** The lens inside the eye.
- **Effect on vision.** If the lens becomes less transparent, it is said to have a cataract. A cataract is not a growth or a film over the eye. It can become worse over time, making vision cloudy. It also affects the perception of colour and can make glare problematic.
- **Cause.** Age is the biggest risk factor. Other common causes include diabetes, trauma and medications such as steroids.
- **Trends.** It is very common to develop a cataract in older age.
- **Treatment.** A straightforward operation can usually remove the misty lens and replace it with an artificial lens.

For more information on cataract, see:

RNIB, Cataracts www.rnib.org.uk/eye-health-eye-conditions-z-eye-conditions/cataracts [last accessed July 2014].

Glaucoma

- **Area affected.** Glaucoma is a term that describes a group of eye conditions that affect the optic nerve. It mainly affects side vision. Central vision (for reading and recognising people) is only affected when glaucoma has advanced to a later stage. This can mean that at the early stages of glaucoma, patients are unaware of problems with their vision.
- **Effect on vision.** Glaucoma can result in tunnel vision, where all side vision is lost and only central vision remains. Blindness is rare from glaucoma if it is diagnosed early enough and drops are taken regularly.
- **Cause.** Someone with a close relative who has glaucoma, is very short sighted or has diabetes has a higher risk of developing glaucoma.
- **Trends.** The most common type of glaucoma is chronic open-angle glaucoma. This affects two in every 100 people over the age of 40. People of black-African or black-Caribbean origin are at an increased risk of developing this type of glaucoma.
- **Treatment.** Glaucoma can be treated with eye drops, laser treatment or surgery. However, the loss of vision in glaucoma is permanent so early diagnosis is important in order to minimise damage to vision. Without treatment, the loss of vision usually gets worse over the course of many months or several years.

More information on glaucoma can be found at the following:

NHS Choices, Glaucoma.

www.nhs.uk/Conditions/Glaucoma/Pages/Introduction.aspx [last accessed July 2014].

RNIB. Glaucoma. www.rnib.org.uk/eye-health-eye-conditions-z-eye-conditions/glaucoma [last accessed July 2014].

Diabetic retinopathy

- **Area affected.** Retinopathy is damage to the retina. A delicate network of blood vessels supplies the retina with blood. High levels of glucose can cause these blood vessels to become blocked, leaky or grow haphazardly. As a result, the retina becomes damaged and is unable to work properly.
- **Effect on vision.** There are three different types of diabetic retinopathy, which vary in their severity and symptoms. Generally, it causes blurred and patchy vision if blood vessels

grow on the retina and loss of central vision if the macula is affected.

- **Cause.** Diabetic retinopathy is caused by prolonged high blood glucose levels. The longer a person has diabetes, the greater the risk of developing diabetic retinopathy.
- **Trends.** Diabetic retinopathy is the most common cause of blindness among people of working age in the UK.
- **Treatment.** To reduce the risk of eye problems, blood glucose, blood pressure and blood fats should be kept within a target range. Depending on the type and stage of retinopathy, treatment may be administered through laser surgery, which lowers the risk of vision loss but cannot reverse damage. Eye surgery called vitrectomy can be carried out if bleeding is severe.

For information on the different types of diabetic retinopathy, see:

Diabetes UK, Eyes (retinopathy) www.diabetes.org.uk/Guide-to-diabetes/Complications/Retinopathy/ [last accessed July 2014].

For information on the different ways diabetes can affect sight, see:

RNIB, Understanding eye conditions related to diabetes www.rnib.org.uk/eye-health-eye-conditions-z-eye-conditions/understanding-eye-conditions-related-diabetes [last accessed July 2014].

Refractive error

- **Area affected.** Refractive errors are a group of eye conditions which mean your eye is unable to focus light correctly on to the retina. There are three types of refractive error: myopia (short sightedness), hypermetropia (long sightedness) and astigmatism.
- **Effect on vision.** The result of refractive errors is blurred vision.
- **Cause.** Often caused by the eye being too long, short, or the cornea too steep or flat.
- **Trends.** Refractive errors are thought to affect approximately a third of the general population.[5] Some cases of refractive error are so severe that they can't be corrected.
- **Treatment.** Treatment depends on the severity of the condition. Those who possess mild amounts of refractive error may elect to

5 Johnstone, P., Refractive error. Ministry of Defence, London, p.10. www.veterans-uk.info/publications/refractive_error.pdf.

leave the condition uncorrected, particularly if the person is asymptomatic. For those who are symptomatic, glasses, contact lenses, refractive surgery, or a combination of the three are typically used.

Further information about refractive errors can be found at:

RNIB, Myopia and high degree myopia. www.rnib.org.uk/eye-health-eye-conditions-z-eye-conditions/myopia-and-high-degree-myopia [last accessed July 2014].

Patient.co.uk, Refraction and refractive errors. www.patient.co.uk/doctor/refraction-and-refractive-errors#ref-2 [last accessed July 2014].

For a fuller and more detailed list of eye conditions, see:

RNIB, Eye conditions. www.rnib.org.uk/eye-health/eye-conditions [last accessed July 2014].

Services for people with sight loss

The following is a brief overview of the services that people with sight loss are likely to engage with and the optional process through which they can be registered as 'sight impaired' (blind) or 'severely sight impaired' (partially sighted).

The UK Vision Strategy produced an Adult UK sight loss pathway to clarify how people with sight loss should get the right support at the right time and from the right person. It can be downloaded as a Word or PDF document from the following page:

UK Vision Strategy, Adult UK sight loss pathway. www.vision2020uk.org.uk/ukvisionstrategy/page.asp?section=299§ionTitle=Adult+UK+Sight+loss+pathway [last accessed July 2014].

Diagnosis & treatment

- **Optometrist.** Registered practitioner, licensed to conduct eye examinations to detect defects in vision, signs of injury, ocular diseases or abnormality. They mainly work in 'high street' practices, although some are based in hospital eye departments and some carry out examinations in people's homes.

- **GPs.** Someone may go to their doctor's surgery for an initial check-up if they are having problems with their sight. The GP should refer them on to an optometrist if they feel that a more specialist intervention is required.
- **Dispensing optician.** Trained to dispense and fit spectacles, contact lenses and other optical aids. They do not carry out eye examinations but work from an optometrist's results.
- **Ophthalmologist.** Medically trained doctor working in hospitals and clinics as an eye physician and in theatre as a surgeon. The ophthalmologist specialises in the medical and surgical care of the eyes.
- **Consultant ophthalmologist.** A consultant ophthalmologist is the only professional that can certify someone as sight impaired or severely sight impaired, using the Certificate of Visual Impairment (CVI). Certification qualifies the person to become registered by the local authority.
- **Othoptist.** Specialises in visual development, binocular vision and eye movements. Othoptists test, assess and offer non-surgical treatment, particularly to patients presenting with double vision, lazy eye and other visual disturbances.

Providers of support after diagnosis

Service provision for people with sight loss varies greatly across the UK. It may be based in a local hospital, located in opticians' practices, made available by local authority sensory impairment teams or offered from a resource centre run by the voluntary sector, such as the local society for people with sight loss. Depending on the local provision, someone might come into contact with:

- **Early advice and information.** This might be provided by an **Eye Clinic Liaison Officer (ECLO)**, a **Hospital Information Officer** or a **Vision Support Service**. They provide those recently diagnosed with an eye condition with practical and emotional support. They can refer and signpost patients to other services, such as social services, housing, GPs and voluntary organisations. They are based in hospital eye clinics and work closely with medical and nursing staff. Not all clinics have such a service and some services cover a number of clinics or are available only on certain days or at certain times.
- **Early reablement.** A **Rehabilitation Officer for Visual Impairment (ROVI)** is a specialist trained in the practical aspects

of sight loss, delivering services in the community. They train people with sight loss to develop and use their existing skills and vision in order to retain independence. Their work may include providing advice on the use of lighting and equipment and training on how to use a long cane or assistive software.

- **Third sector support.** There are a number of local and national organisations offering advice, information and support to people with sight loss. A list of them can be found at:
Action for blind people, National sight loss organisations
<https://www.actionforblindpeople.org.uk/resources/where-to-get-help/national-sight-loss-organisations/> [last accessed July 2014].

For a presentation detailing these roles further, see:

Bairstow, B (2010) Who's who? From optometrist to ophthalmologist... and everyone in between. A guide to everyone involved in eyecare. <http://kt-equal.org.uk/uploads/Mary%20Bairstow%207%20March%202013.pdf> [last accessed July 2014].

The registration process

The purpose of registration is to provide a gateway to enable someone with sight loss to access welfare benefits and adult social care services.

In order to be registered, first the individual needs to be certified as either 'sight impaired' (partially sighted) or 'severely sight impaired' (blind) by a consultant ophthalmologist. The local authority has a statutory responsibility to hold the register although this may be contracted out to a third sector organisation.

Certifying sight loss

The typical route someone takes to be certified is outlined below and is detailed in the Adult UK sight loss pathway that can be downloaded from [this page](#):

1. The individual sees an optometrist on the high street or their GP. If necessary, the optometrist will refer them to an eye clinic. This usually happens when the optometrist feels that they can do nothing more for the person. However, if the person has low vision or may be at risk (from falling, for instance) but is not yet at a stage to be certified, the optometrist can make a direct referral for rehabilitation using the Low Vision Leaflet (LVL). The

optometrist may also run their own low vision clinic at which the person may be prescribed low vision aids (e.g. a magnifier) to support independence.

2. At the eye clinic, a consultant ophthalmologist assesses the patient's vision and eyes to decide if the patient is eligible for their sight loss to be certified. The test is based on best-corrected vision in each of the eyes, which means that the patient must wear up-to-date glasses or contact lenses for the test.
3. Consultant ophthalmologists follow guidelines about the level and nature of sight loss in order to determine if someone should be certified at all. For example, consultants will only certify a patient's sight loss if it is thought not to be treatable by non-surgical or surgical intervention. A patient whose sight loss qualifies will be certified as either 'sight impaired' or 'severely sight impaired'. To see these guidelines, go to:

RNIB, The criteria for certification. www.rnib.org.uk/eye-health-registering-your-sight-loss/criteria-certification [last accessed July 2014].

4. A patient will receive a Certificate of Vision Impairment (CVI) if in England and Wales, a Certification of Blindness or Defective Vision (BP1) if in Scotland and an A655 if in Northern Ireland.
5. The document is sent to the patient, their GP, and the local social services department. This should happen within 5 days of its completion at the hospital.
6. Another copy is sent to the Certifications Office at Moorfields Eye Hospital for epidemiological analysis of new certifications including data on the causes of visual impairment.
7. The person may not yet be certified but may have significant sight loss. In this instance a referral may be made from the eye clinic to a Low Vision Clinic where they may be prescribed low vision aids. Low Vision Clinics can be run by a local sight loss society, commissioned by the Clinical Commissioning Group or run by a High Street Optometrist.

Registering sight loss with social services

Once someone's sight loss is certified, they can choose whether they become registered with their local social services department. It is entirely voluntary.

The typical route to becoming registered with social services is as follows:

- **Initial Contact.** Within 14 days of the social services department receiving the CVI, it should contact the individual to ask if they wish to be registered. This can happen by post or telephone. If the individual wishes to be registered, their name will be put on a list held by their social services department. The purpose of the register is to help the local authorities plan and provide services for children and adults who have a visual impairment. The register is confidential.
- **Assessment of visual impairment needs.** The Department of Health and Social Services Inspectorate recommends that a full assessment occurs within 4 weeks of the CVI being received. This stage is carried out over the telephone or in the person's home.
- **Rehabilitation.** Rehabilitation is the structured support put in place by a local authority or by an agency commissioned by the local authority. Rehabilitation is a specialist intervention, which addresses mobility and orientation, communication and independent living skills. It might include the teaching of skills and techniques on how to cook safely, how to use technology that aids independence or how to use a white cane. RNIB provides useful information on rehabilitation services in its campaign toolkit. Its briefings can be downloaded from:

RNIB, Rehabilitation services campaign toolkit.

www.rnib.org.uk/campaigning-campaign-resources-national-campaign-resources/rehabilitation-services-campaign-toolkit [last accessed July 2014].

Community Care Assessment. This stage only applies to those that have outstanding needs after a rehabilitation assessment and programme. If the assessment finds that someone is deemed eligible according to Fair Access to Care Services (FACS), they may become eligible for certain services, including personal care if required. Other services, including provision of equipment and home adaptations, may also be provided by the local authority and are not dependent on a FACS assessment e.g. adaptations can be provided through Disabled Facilities Grants.

The local authority can also make a **direct referral** for rehabilitation using the Referral of Visual Impairment (RVI). This

referral may be for someone who is already registered and has been through the pathway before or for someone with low vision who is at risk (for instance, at risk of falling or having an accident due to their sight loss).

If someone chooses not to be registered:

- The local council still has a legal duty to advise the individual of the range of services available and to carry out an assessment of their needs.
- A Low Vision Leaflet (LVL) available from the optometrist and a Referral of Vision Impairment (RVI) from the eye clinic can be completed by a health professional and sent to the local authority.

It is important to note that, in practice, the route to Certification and Registration does not always reflect how it is outlined here. It varies across local authorities depending on resources such as staffing levels and funding. This also applies to the LVL and RVI which are underused in many areas.

RNIB commissioned the following research that highlights some of these inconsistencies:

Boyce, T., (2012) The certification and registration processes: stages, barriers and delays. RNIB, London. The briefing and the full report can be downloaded from www.rnib.org.uk/knowledge-and-research-hub-research-reports/early-reach-research.

Concessions once someone is registered

If someone chooses to be registered, they are automatically considered 'disabled' under the Equality Act. Registering is also accompanied by the following benefits depending on whether someone is registered as sight impaired or severely sight impaired.

Concessions for those registered **severely sight impaired** (blind) include:

- Half price TV licence
- Car parking concessions
- Free postage on items that have been prepared for blind and partially sighted people, such as braille items and books in large print.

Concessions for those registered **either sight impaired or severely sight impaired** (either blind or partially sighted) include:

- Free NHS eye test
- Help with other NHS costs
- Travel concessions such as the Disabled Person's Railcard and bus pass
- Leisure concessions, such as discounts to museums and exhibitions
- Benefits – registration does not automatically entitle someone to any benefits but it can be used as supporting evidence when applying for benefits such as Personal Independence Payment (PIP).

For more information on the concessions available, go to:

RNIB, (2013) Starting out: benefits, concessions and registration. RNIB, London. It can be downloaded as a Word or PDF document at this link www.rnib.org.uk/information-everyday-living-benefits-and-concessions/concessions [last accessed July 2014].

Prevalence of sight loss

The nature of the statistics

There is no precise figure for the number of people affected by sight loss. Numbers vary depending on the definition applied and the data collection method used. Three methods are outlined below: administrative (such as certification and registration figures); an estimate based on the commonality of eye conditions; and secondary analysis of general population surveys.

Administrative figures

Data sources on the number of people with sight loss include:

- **Benefits statistics.** Information based on the number of benefit claimants.
- **Certification figures.** Information based on clinical measures. For example, someone is defined as 'severely sight impaired' if their visual acuity measures lower than 3/60 in the Snellen test. An explanation of these figures is found at:

RNIB, The criteria for certification www.rnib.org.uk/eye-health-registering-your-sight-loss/criteria-certification [last accessed July 2013].

- **Registration figures.** Information based on the number of people registered blind or partially sighted by local authorities. This means that someone has agreed to be added to the register. It does not necessarily mean that they are in receipt of services.

Registration figures receive much attention in the sight loss sector. Further information on the nature and limitations of these statistics is given below.

In England, Scotland and Wales, 174,724 people are registered as severely sight impaired (blind) and 175,084 are registered as sight impaired (partially sighted). Northern Ireland does not publish registration figures, yet it is estimated at 8,200. In total, therefore:

358,000 people are registered as severely sight impaired or sight impaired in the UK. [6]

This figure denotes the number of people registered with social services, rather than certified with their consultant ophthalmologist. It is thought that many people are not certified or registered, despite their eligibility. This may be due to the following:

- Registration is voluntary, and some people might be reluctant to be registered as blind or as having a disability.
- Clinicians and patients might have insufficient information and education about the purpose of certification and the potential benefits of registration.

The following studies evaluate the statistics that grow out of the certification and registration processes:

The Royal College of Ophthalmologists (2012), Summary of Certificate of Vision Impairment Survey December 2012. The Royal College of Ophthalmologists, London.

6 RNIB (2013), Sight loss UK 2013: the latest evidence. RNIB, London, p.6. www.rnib.org.uk/sites/default/files/Sight_loss_UK_2013.pdf [last accessed July 2014].

www.rcophth.ac.uk/news.asp?section=24&itemid=1265 [last accessed July 2014].

Douglas, G., Pavey, S. and Corcoran, C. (2008), Network 1000: Access to information, services and support for people with visual impairment. www.birmingham.ac.uk/Documents/college-social-sciences/education/victar/network1000-access-to-information-services-support.pdf [last accessed July 2014].

Boyce, T., (2012) The certification and registration processes: stages, barriers and delays. RNIB, London.

Furthermore, the 358,000 registered individuals do not include those who cannot be certified or registered because:

- Their visual field and visual acuity is seriously limited but it is not limited enough to meet the criteria for certification.
- Their sight loss is not thought to be permanent.
- They are on the waiting list for treatment e.g. cataract surgery.

Estimate based on the prevalence of eye conditions

RNIB has used evidence to estimate that 1.87 million people in the UK are living with sight loss.[7] This indicates that the true picture is of a largely unregistered visually impaired population.

The figure of 1.87 million includes those who are registered, but also those who are waiting for treatment, those whose sight could be improved, those who have not registered for whatever reason and people whose sight loss is not at a level that allows them to register. For example, someone with a serious uncorrected refractive error that could be improved with correct lenses is seen to be 'living with sight loss'.

Population surveys

National, general population surveys often include questions about sight loss. This offers another means of obtaining prevalence data, but relies on people with sight loss identifying themselves.

7 RNIB (2013), Sight loss UK 2013: the latest evidence. RNIB, London, p.6. www.nib.org.uk/sites/default/files/Sight_loss_UK_2013.pdf [last accessed July 2014].

Secondary analysis of this publicly available data is a useful and cost effective method of research. However, surveys employ a variety of methods, definitions and thresholds to establish whether or not respondents have sight related problems.

Most commonly, surveys ask if the respondent has any 'disability' or 'health condition'. For example, in the Labour Force Survey, respondents are asked 'Do you have any health problems or disabilities that you expect will last for more than a year?' Although the question is designed to identify those people who can be regarded as disabled according to the DDA definition, they still rely on participants answering the questions accurately. If they answer 'yes', they are able to choose from a list of 17 categories, one of which is 'difficulty in seeing (while wearing spectacles or contact lenses)'.^[8]

Population surveys might fail to identify the presence of sight loss because:

- People may not regard their sight loss as a 'disability' or 'health condition'.
- Often only one type of condition is coded, and the respondent may view their sight loss as a lower priority than another condition.
- It is often not made clear in the question whether or not respondents should include sight loss that can be corrected by optical aids or surgery, or if the effect it has on their everyday lives should be measured with or without the use of low vision aids.

For guidance on the use of national survey data in visual impairment research, see:

McManus, S. and d'Ardenne, J. (2012) Using national survey data in visual impairment research: summary guide. NatCen Social Research and Thomas Pocklington Trust, London. A PDF version can be downloaded from www.pocklington-

8 Hewett, R. (2013), Investigation of data relating to blind and partially sighted people in the Quarterly Labour Force Survey: October 2009 to September 2012. RNIB, London, p.7. The full report and briefing can be downloaded from www.rnib.org.uk/knowledge-and-research-hub-research-reports/employment-research

trust.org.uk/Resources/Thomas%20Pocklington/Documents/PDF/Research%20Publications/NATCEN%20Summary_guide-%20Final%20June%202012.pdf [last accessed July 2014].

MacManus, S. and Lord C. (2012), Circumstances of people with sight loss: Secondary analysis of Understanding Society and the Life Opportunities Survey. NatCen Social Research, London. www.rnib.org.uk/sites/default/files/Circumstances_sight_loss_report.pdf [last accessed July 2014].

Hewett, R. (2013), Investigation of data relating to blind and partially sighted people in the Quarterly Labour Force Survey: October 2009 to September 2012. RNIB, London. The full report and briefing can be downloaded from www.rnib.org.uk/knowledge-and-research-hub-research-reports/employment-research

Trends

Age

Sight loss affects people of all ages, but it is especially common in older people. With an ageing society, increasing numbers of people will experience sight loss.[9]

One in five people aged 75 and over are living with sight loss. One in two people aged 90 and over are living with sight loss.[10]

On the basis of the estimate that almost two million people are currently living with sight loss, it is projected that by 2050 there will be almost four million people living with sight loss in the UK.[11]

Income

Analysis of the English Longitudinal Study of Ageing showed that those with sight loss are more likely to be in poor social economic circumstances.[12]

9 Sight loss UK 2013: the latest evidence. RNIB, London, p.9. www.rnib.org.uk/sites/default/files/Sight_loss_UK_2013.pdf [last accessed July 2014].

10 RNIB, Key information and statistics. www.rnib.org.uk/knowledge-and-research-hub/key-information-and-statistics [last accessed July 2014].

11 Access Economics (2009), Future sight loss UK 1: the economic impact of partial sight and blindness in the UK adult population. RNIB, London, p.44.

Research published in 2011 confirmed that people on lower incomes are at a greater risk of sight loss as a result of lower uptake of screening, referral and treatment.[13]

Ethnicity

People from black and minority ethnic communities may be at greater risk of some of the leading eye conditions. For example, the black and Asian populations have a greater risk of developing diabetic eye disease compared to the white population. Conversely, the white population has a greater risk of developing refractive error compared to the black population. Although some people from minority groups may have a greater risk of eye diseases, the evidence suggests that they do not receive the same level of access to eye care services.[14]

RNIB commissioned the following review of the evidence relating to the cause of inequalities in eye health, with particular reference to ethnicity, age and socio-economic deprivation.

Johnson, M., Cross, V., Scase, M., Szczepura, D., Hubbard, W., Claringbull, K., Simkiss, P. and Leamon, S. (2011), A review of evidence to evaluate effectiveness of intervention strategies to address inequalities in eye health care. RNIB, London. The briefings and the report can be downloaded from www.rnib.org.uk/knowledge-and-research-hub-research-reports/prevention-sight-loss [last accessed July 2014]

Multiple disability

Sight loss is often concurrent with other health or mobility problems and social changes associated with ageing.¹⁵

12 Nazroo, J. & Zimdars, A. (2010) Social Inclusion, social circumstances and the Quality of life of visually impaired older people. Research Findings 32. Thomas Pocklington Trust, London. <http://www.pocklington-trust.org.uk/Resources/Thomas%20Pocklington/Documents/PDF/Research%20Publications/RF32.pdf>

13 Johnson et al. (2011), A review of evidence to evaluate the effectiveness of current models and intervention strategies to promote primary and secondary eye health care. RNIB, London.

14 Access Economics (2009), Future sight loss UK 1: the economic impact of partial sight and blindness in the UK adult population. RNIB, London, p.154.

15 Thetford, C., Robinson, J., Knox, P., Mehta, J and Wong, D. (2009), Occasional paper Number 17: The changing needs of people with sight loss. Thomas Pocklington Trust, London, p.8. www.pocklington-trust.org.uk/researchandknowledge/publications/rf20op17

Researchers have commented that when working with participants with sight loss, their needs were better catered for if visual impairment were viewed as one part of the whole picture. While some people may view their sight loss as the main obstacle to their independence and mobility, others may see it as a low priority in the context of their other needs.

A study known as Network 1000 conducted in 2006 found that 70% of respondents had long term health problems or disabilities other than their visual impairment.[16] The conditions that most commonly accompany sight loss are as follows.

Hearing loss

43% of visually impaired people reported having difficulty with their hearing.[17]

Mobility issues and arthritis

As sight loss is more commonly found in older people, research teams should take into account potential mobility issues. A respondent to the Network 1000 survey said: 'I could deal with the visual impairment as it's been over 15 years, but it's the arthritis in my knee that holds me back more.'[18]

Learning difficulties

Adults with learning disabilities are ten times more likely to be blind or partially sighted than the general population.[19] Often, very

16 Douglas, G., Corcoran, C. and Pavey, S. (2006) Network 1000: Opinions and circumstances of visually impaired people in Great Britain. Visual Impairment Centre for Teaching and Research, University of Birmingham, p.7. www.vision2020uk.org.uk/core_files/Full%20Network%201000%20report%20-%20FINAL%20VERSION%20September%2006-MASTER.pdf [last accessed July 2014].

17 Douglas, G., Corcoran, C. and Pavey, S. (2006) Network 1000: Opinions and circumstances of visually impaired people in Great Britain. Visual Impairment Centre for Teaching and Research, University of Birmingham, pp.7-8.

18 Douglas, G., Corcoran, C. and Pavey, S. (2006) Network 1000: Opinions and circumstances of visually impaired people in Great Britain. Visual Impairment Centre for Teaching and Research, University of Birmingham, p.46.

19 Emerson, E. and Robertson, J. (2011) The estimated prevalence of visual impairment among people with learning disabilities in the UK. RNIB and SeeAbility, London.

little is known about how much a person with a learning disability can actually see, making it difficult for carers to know how to support the person to make best use of their vision. SeeAbility is a charity that supports people who are visually impaired with additional disabilities. Their website can be found at www.seeability.org.

Dementia

Sight loss affects at least 123,000 people with dementia[20]. It can be caused by normal ageing of the eye or the dementia itself. Sight loss is typically under-diagnosed in people with dementia because the signs can be difficult to separate. Behaviour such as becoming withdrawn, being confused and disoriented and falling more could be a reaction to sight loss or attempts to make the most of useful vision.

For further information about sight loss and dementia:

Social Care Institute for Excellence, Dementia Gateway
www.scie.org.uk/publications/dementia/living-with-dementia/sensory-loss/ [last accessed July 2014].

RNIB Scotland and Alzheimer Scotland, Dementia and sight loss (2012)
www.rnib.org.uk/sites/default/files/RNIB%20Alzheimers%2020pp%20Booklet%20v2%20Proof.pdf [last accessed July 2014].

Lawrence, V., Murray, J., Banjeree, S. and ffytche, D. (2008), The experiences and needs of people with dementia and serious visual impairment: a qualitative study. Thomas Pocklington Trust, London. The Research Findings and the Occasional Paper can be found at www.pocklington-trust.org.uk/researchandknowledge/publications/rf19op16.htm [last accessed July 2014].

www.disability.co.uk/sites/default/files/resources/Learn_dis_small_res.pdf [last accessed July 2014].

20 Jones, R and Trigg R (2007) Dementia and serious sight loss. Research Findings, 11. Thomas Pocklington Trust, London. <http://www.pocklington-trust.org.uk/Resources/Thomas%20Pocklington/Documents/PDF/Research%20Publications/OP11.pdf>

Stroke

Following a stroke, there are a range of longer-term problems that someone might continue to face, such as visual, cognitive and communication. Up to two thirds of people experience some changes to their vision. The type of visual problem – whether that is a some loss of vision or problems with eye movement or visual processing – depends on exactly where in the brain the stroke occurred.

Some people might see some improvement in their vision up to four months following a stroke. This is highly dependent on where the damage in the brain has happened, the type of stroke and other existing health problems.[21]

For more information, see:

Stroke Association (2012), Visual problems after stroke. Stroke Association, London.

www.stroke.org.uk/sites/default/files/F37_Visual%20problems%20after%20stroke_0.pdf [last accessed July 2014].

RNIB, Stroke and sight loss www.rnib.org.uk/eye-health-sight-loss-and-other-conditions/stroke-and-sight-loss [last accessed July 2014].

Rowe, F. (2014), Vision care for stroke survivors. Thomas Pocklington Trust, London. Research Findings Number 40 can be downloaded from www.pocklington-trust.org.uk/researchandknowledge/publications/rf40.htm [last accessed July 2014].

Diabetes

Diabetes can cause a number of problems with the eye. If diabetes is well controlled there is a lower risk of sight complications. The most serious complication is diabetic retinopathy. The risk of developing it is reduced by having regular eye checks, not smoking and controlling sugar levels, blood pressure and cholesterol.

21 RNIB, Stroke related eye conditions www.rnib.org.uk/eye-health-eye-conditions-z-eye-conditions/stroke-related-eye-conditions [last accessed July 2014].

Making the most of 'useful vision'

If someone has a reduced level of vision that cannot be improved with glasses or any other treatment, they are said to have 'low vision'.

Less than 5% of people with sight loss have no sight or light perception. The majority have some useful vision. The level of useful vision can vary depending on wellbeing, tiredness, the task in question and the time of day.

'Low vision aids' are pieces of equipment that can help to make the best use of residual vision (remaining eyesight) by changing the size, contrast or light levels. These aids are often trialled and tailored to individual needs with an optometrist during a low vision assessment.

The most common types of low vision aids are listed below, divided into optical and non-optical aids:

Optical low vision aids:

- **Magnifiers.** Magnifiers come in different strengths and sizes. They can be hand-held, made to rest flat on the page or hung around the neck to help with hands free activities such as sewing. Stand magnifiers can be fitted with lights to illuminate the object being viewed.
- **Telescopic devices for faraway objects.** Faraway objects can be viewed with the use of a monocular (for one eye) and binocular (for both eyes). They can be used for distance tasks such as watching a play at the theatre and reading notice boards and bus numbers.
- **Typoscopes.** These are made of black card or plastic with holes cut in them to act as a guide when reading and writing. They cut out glare to allow the user to concentrate on the area of interest.
- **Task lighting.** Good, well-positioned lighting makes many tasks easier to perform.

For a more detailed description of optical low vision aids and useful pictures showing them in use, see:

Macular Society (2013), Low vision aids. Macular Society, London.
www.macularsociety.org/Resources/Macular%20Disease/Docume

<https://www.rnib.org.uk/Help/accss/Low%20vision%20aids.pdf> [last accessed July 2014].

Non-optical low vision aids include:

- Signage guides
- Bold-print books
- Liquid level indicators
- Writing and labelling equipment
- Talking kitchen appliances
- Amplified phones with large buttons

To see the wide range of low vision aids available, go to RNIB's online shop at www.shop.rnib.org.uk/page/home.

Electronic low vision devices:

Images can be projected onto a computer screen with the use of a range of assistive software. The image can then be further magnified or its colours and contrast manipulated to match individual preferences. Chapter 6 describes the different ways people with sight loss can use computers.

Mobility aids

- **Guide dogs.** The term 'guide dog partnership' refers to the dog and the owner. The function and purpose of a guide dog is to guide the person around obstacles and indicate the location of steps and kerbs. It is the guide dog owner, not the dog, who directs the partnership. There are over 4,700 guide dog owners in the UK.
- **Symbol cane.** The symbol cane is used purely as a sign that the person has a visual impairment and is not used as a mobility aid. When in use, it is extended and carried diagonally across the body, and is most often used when waiting to cross a road or in crowded situations. It is never long enough to reach the ground.
- **Guide cane.** A guide cane is used to help people with sight loss locate such things as kerbs and steps. It is not a full mobility aid but gives a good idea of the surrounding area and acts as a visual signal to others.
- **Long cane.** A long cane is a full mobility aid. Most long canes fold up for ease of carriage, but others are long and rigid. They are moved in a sweeping movement as the person walks along

and give a good idea of the ground underfoot, as well as locating kerbs, steps and other obstacles.

The above summarises the following guide:

Modern Eyes Training Services Ltd (2006), Out and about with VIPs. Modern Eyes Training Services, Stroud.
www.community.stroud.gov.uk/documents/23_Out_and_about_with_VIPS_Visually_Impaired_Persons.pdf [last accessed July 2014].

Prevention

Around half of the estimated 1.87 million cases of sight loss are preventable or treatable if detected early enough.[22]

It is thought that almost two thirds of sight loss in older people is caused by serious refractive error and cataract. Both conditions can be diagnosed by an eye test. In most cases, sight can be improved by wearing correct glasses or cataract surgery.[23]

People over 60 are entitled to a free test under the NHS every two years, and over 70 every year. Free eye tests are available for those under 60 if:

- They are registered as sight impaired or severely sight impaired
- They are diagnosed with diabetes or glaucoma
- They are over 40 and one of their parents, siblings or children has been diagnosed with glaucoma

In Scotland, everyone is entitled to a free test, regardless of age.[24]

Experience of sight loss

22 Access Economics (2009), Future Sight Loss UK 1: Economic Impact of Partial Sight and Blindness in the UK adult population. RNIB.

23 RNIB, Key information and statistics. www.rnib.org.uk/knowledge-and-research-hub/key-information-and-statistics [last accessed July 2014].

24 Age UK (2012), Caring for your eyes. Age UK, London, p.3.

www.ageuk.org.uk/Documents/EN-GB/Information-guides/AgeUKIG37_Caring_for_your_eyes.inf.pdf?dtrk=true [last accessed July 2014].

Range of experience

The reality of sight loss varies for each individual. While someone might have problems seeing small details on a television screen, others might find it difficult to make out the buttons on a remote control and a very small minority will be unable to see the screen at all.

Some people with sight loss read books in standard print and some read large print; some might use a magnifier to read a short newspaper article, while others may not be able to read a poster on a bus or advertising boarding. Others cannot read any print and may use braille, audio or electronic versions where available.[25]

It is important to consider the range of experiences among people with sight loss. For example, someone born with sight loss may describe their circumstances differently to someone that lost their sight in their twenties or in their sixties.

This range of experience means that the most important factor in the design and delivery of services is the recognition that people with sight loss have highly individual needs.

Employment

Two-thirds of those of working age who are registered sight impaired or severely sight impaired are not in paid employment.[26]

For further information and statistics, see:

RNIB (2013), Evidence-based review: people of working age.
RNIB, London

www.rnib.org.uk/sites/default/files/RNIB_evidence_based_review_of_working_age_people.pdf [last accessed July 2014].

The Access to Work scheme is run by Jobcentre Plus. It reimburses an employer for providing an employee with the

25 RNIB (2012), Safe statistics and key messages about sight loss. RNIB, London. www.vision2020uk.org.uk/core_files/Safe_stats_v3_-_Final.doc [last accessed July 2014].

26 Action for blind people, Facts and figures about issues around sight loss <https://www.actionforblindpeople.org.uk/about-us/media-centre/facts-and-figures-about-issues-around-sight-loss/> [last accessed July 2014].

equipment necessary to perform the job, such as a screen reader or braille keyboard. For further guidance provided by the Department for Work and Pensions, see:

Department for Work and Pensions (2013), Employing disabled people and people with health conditions gives further guidance www.gov.uk/government/publications/employing-disabled-people-and-people-with-health-conditions/employing-disabled-people-and-people-with-health-conditions [last accessed July 2014].

Psychological impact

The impact of sight loss is dependent on numerous factors: the severity of visual impairment, age at onset, how well remaining vision is used, presence of additional disabilities, quality of intervention services and various personal and individual factors.

Previous research has found that individuals who had been blind or partially sighted from birth were better adapted to their situation because it was all they had ever known.²⁷ Someone who acquires sight loss later on in life might experience isolation or feelings of loss or bereavement. This will vary, however and while it is worth considering the age of onset, it can only tell us so much about someone's accessibility requirements and how they identify with their condition.

For information on the psychological impact of sight loss, see:

Hodge, S. and Eccles, F., Loneliness, social isolation and sight loss: a literature review conducted for Thomas Pocklington Trust. Thomas Pocklington Trust, London. A PDF version of the report can be found at

www.eprints.lancs.ac.uk/68597/1/loneliness_social_isolation_and_sight_loss_final_report_dec_13.pdf [last accessed July 2014].

²⁷RNIB (2009), Understanding the needs of blind and partially sighted people: their experiences, perspectives and expectations. RNIB, London, p.7. www.uk.sagepub.com/gargiulo4emedia/study/chapters/encyclopedia/encyclopedia12.2.pdf. Also see Bruce, S. (2004), Visual impairment across the life span, Encyclopaedia of Applied Developmental Science. SAGE Publications. A PDF version is available from www.uk.sagepub.com/gargiulo4emedia/study/chapters/encyclopedia/encyclopedia12.2.pdf [last accessed July 2014].

RNIB (2013), Facing blindness alone: what government needs to do now to stop the isolation of blind people. RNIB, London. A PDF version of the report can be found at www.rnib.org.uk/sites/default/files/Facing%20blindness%20alone%20Campaign%20report.pdf [last accessed July 2014].

MacManus, S. and Lord, C. (2012), Circumstances of people with sight loss: secondary analysis of Understanding Society the Life Opportunities Survey. RNIB and NatCen Social Research, London www.rnib.org.uk/sites/default/files/Circumstances_sight_loss_report.pdf [last accessed July 2014].

Helpful resources

The statistics used most commonly in the sight loss sector

UK Vision Strategy. Sight loss statistics.
<http://www.vision2020uk.org.uk/ukvisionstrategy/page.asp?section=302§ionTitle=Sight+loss+statistics>

RNIB (2013), Sight loss UK 2013: the latest evidence. RNIB, London, p.6.
www.rnib.org.uk/sites/default/files/Sight_loss_UK_2013.pdf [last accessed July 2014].

Access Economics (2009), Future sight loss UK 1: the economic impact of partial sight and blindness in the UK adult population. RNIB, London.

The certification and registration process

UK Vision Strategy, Adult UK sight loss pathway.
www.vision2020uk.org.uk/ukvisionstrategy/page.asp?section=299§ionTitle=Adult+UK+Sight+loss+pathway [last accessed July 2014].

The Royal College of Ophthalmologists, Certificate of Vision Impairment. By clicking on the following link, you will find several downloadable documents that provide information on the process

www.rcophth.ac.uk/page.asp?section=165§ionTitle=Certificate+of+Vision+Impairment [last accessed July 2014].

Boyce, T., (2012) The certification and registration processes: stages, barriers and delays. RNIB, London. The briefing and the full report can be downloaded from www.rnib.org.uk/knowledge-and-research-hub-research-reports/early-reach-research

The experiences of people with sight loss

Hodge, J., Knox, P., Robinson, J., Thetford, C. (2013), As life goes on: a closer look at how support services respond to the changing needs of people with sight loss, Thomas Pocklington Trust, London.

Douglas, G., Corcoran, C. and Pavey, S. (2006) Network 1000: Opinions and circumstances of visually impaired people in Great Britain. Visual Impairment Centre for Teaching and Research, University of Birmingham.

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