

Sight Loss in Adults

Summary

- An estimated 23,500 people in Hampshire over the age of 18 have some degree of sight loss. It is more common in older people and as the population of Hampshire ages, the prevalence of sight loss is likely to increase with up to 30,000 people in Hampshire affected by sight loss by 2020.
- Children and young people with sight loss are a vulnerable group.
- A range of public, private and third sector organisations currently support people with visual impairment in Hampshire.
- People accessing eye healthcare tending to use a range of NHS, local authority and third sector resources, but signposting could be improved. There is a need for better access to information, particularly at first contact, both about conditions and also about where to go to find other support or services that might help manage those conditions.
- Out of a choice of five priority areas for development, local service users said they primarily wanted to receive their services close to where they live, make sure they receive a prompt service and ensuring the type of information and advice they need is available.

Recommendations

It is recommended that healthcare providers, commissioners, GPs, Optometrists, local authorities, third sector eye health organisations and other relevant stakeholders work together to:

- Raise awareness of the consequences of sight loss and the health conditions and other factors that lead to sight loss.
- Ensure there is adequate and appropriate availability of low vision assessment supported by a coordinated county-wide provision of a range of low vision support services including aids, equipment and training.
- Provide better support and information at point of diagnosis or shortly after.
- Ensure that there is a coordinated range of local and national resources that will provide people with the information they require on their eye condition, including but not limited to, for example, what support and services there are available, how to register or access financial support and how to live with their eye condition.
- Develop and adopt a Hampshire wide statutory and third sector sight-loss / eye health pathway.
- Ensure that there are systems supported by the appropriate governance to enable the sharing of information between services so individuals can receive more targeted support and services.

Sight Loss in Adults

1. Introduction

The term 'sight loss' is used to describe the breadth of visual impairment, from people who are partially sighted to people who are blind. Sight loss can be congenital or acquired at any age and affects people in different ways. Most people who may be called 'blind' have some light recognition and may be able to recognise family and friends. Other people will have no central vision or no vision to the sides, others may see a patchwork of blank and defined areas, or else everything may be seen as a vague blur.

Developing any form of sight loss is a life-changing experience – it is the sense that people fear losing the most. Sight loss can lead to difficulties in getting around and accessing information and some people with sight loss feel isolated and that they lose their independence with affected emotional wellbeing. It also impacts on family and friends. However, access to different types of information and support from a range of services such as social services, health and voluntary sector organisations, people with sight loss can retain or regain their independence. This includes accessible information, access to appropriate aids, information and advice, rehabilitation for people who lose their sight so they can gain the skills and confidence to carry out day-to-day tasks, and support with getting around.

Sight loss becomes more common with age. It is estimated that around 2 million people in the United Kingdom live with sight loss, with around 100 people starting to lose their sight every day.¹ However it is also estimated that 50% of these people could have their sight improved by wearing correctly prescribed glasses or having the right treatment at the right time.

In economic terms, in 2009/10 direct NHS eye health care expenditure was at least £2.3 billion, with an indirect cost (informal and formal care and lower employment rates) of sight loss on the UK economy, in 2008, estimated at £4.6 billion.

There are numerous organisations in the public, private and third sector supporting people with sight loss nationally and across Hampshire. These are often dispersed, although over recent years greater efforts have been made to work in partnership.

In April 2008 Vision 2020, an umbrella organisation facilitating greater collaboration and co-operation between UK organisations and people focusing on vision impairment and led by the RNIB, launched the "UK Vision Strategy" (Vision 2020, 2008), a document to set the direction for eye health and sight loss services across the UK. It is underpinned by the following values:

- Fair and equitable access for all members of society to eye health, eye care and sight loss services.
- Person-centred delivery of excellent services and support in the most appropriate way for each individual.
- Evidence-based policies and services to guide resource allocation and effective services.
- Awareness of and respect for people with sight loss and full compliance with equality legislation.

The UK Vision Strategy identifies three strategic outcomes areas:

¹ The prevalence of visual impairment in the UK: A review of the literature, Tate et al, RNIB (2005)

Sight Loss in Adults

- Improving the eye health of the people of the UK.
- Eliminating avoidable sight loss and delivering excellent support for people with sight loss.
- Inclusion, participation and independence for people with sight loss.

Recently a Hampshire Vision Partnership Group, supported by many of the local sight loss support organisations, was set up to support implementation of the UK Vision Strategy in Hampshire. The group's purpose is to provide a strategic lead and deliver on the implementation and evaluation of the eye care and sight loss services in Hampshire. This is being done by developing a strategic and combined sight loss pathway to provide greater support for people with sight loss.

2. The scale of sight loss

The RNIB suggests that without action, the numbers of people with sight problems in the UK are likely to increase dramatically over the next 25 years.² They estimate that every day in the UK approximately 100 people start to lose their sight. In addition there is very strong evidence that the prevalence of conditions that result in sight loss increases with age, and the UK population is ageing.

2.1 Risk factors

The main cause of avoidable sight loss in the working age population is diabetic complications. Most people who have diabetes will have some damage to their retinal vessels in the eye within 10 years of having diabetes. To this end a national screening programme offers screening to all diabetics over the age of 12 years annually to screen for diabetic retinopathy. While data suggest that a significant proportion of diabetics in Hampshire have yet to be diagnosed, it is predicted that the number of people, in Hampshire, aged over 65 who will have diabetes will increase by 51% over the next 20 years (approximately 31,900 (2012) to around 48,200 (2030)).

Other risk factors for sight loss include:

- Smoking: research shows that smokers face a higher risk of losing their sight compared to non-smokers. Research has also shown that the link between smoking and sight loss is a strong incentive for people to stop or reduce the amount they smoke³.
- Learning disabilities: people who have a learning disability are more likely to have a visual problem as part of the underlying cause of their learning disability. This likelihood increases with the severity of the learning disability and with age. Overall, 30% of people with a learning disability are estimated to have a significant visual impairment⁴.
- Stroke: every year an estimated 150,000 people in the UK suffer from a stroke. Visual problems are not unusual as a result of a stroke. The damage the stroke does in the brain impacts the visual pathways of the eye which can result in visual field loss, blurry vision, double vision and moving images.

² Action For Blind, internet factsheet (<http://www.actionforblindpeople.org.uk/about-us/media-centre/facts-and-figures-about-issues-around-sight-loss/>) accessed April 2012

³ Age-Related Macular Degeneration and Associated Risk Factors, AMD Alliance International Campaign, 2005

⁴ Action for health - health action plans and health facilitation: detailed good practice guidance of implementation for Learning Disability Partnership boards, Department of Health, July 2002, p33

Sight Loss in Adults

2.2 Effects of sight loss

The implications and effects of sight loss include:

- Falls: a review of 31 studies on the risks and type of injuries associated with sight loss suggest that those with sight loss are 1.7 times more likely to have a fall and 1.9 times more likely to have multiple falls.
- Emotional wellbeing and depression: losing sight can have a profound impact upon a person's emotional wellbeing. Older people with sight loss have a higher incidence of depression than sighted people (13.5% of older people with sight loss experience depression compared to 4.6% of people with good vision)⁵.

Children and young people (0-25 years) with sight loss are vulnerable, requiring high levels of appropriate support. It is recognised that children and young people with sight loss, if provided with appropriate levels of quality education and support, will maximise their life chances in terms of health, social inclusion and economic participation in society. Unfortunately, the opposite is also true.

3. Level of need in Hampshire

Age-related eye conditions are the most common cause of sight loss in the UK. The vast majority of people with sight problems in the UK are aged seventy-five or over. It is estimated that 5.6% of people aged 65 to 74, 8.5% of people aged 75 to 84 and 26.8% of people aged 85 and over in the community had a sight loss at a level that would be registerable as blind or partially sighted⁶.

An estimate of the numbers of the working age population registerable as blind or partially sighted is around 80,000 people. This equates to 1 in 500 people in the UK aged 18 to 64 with a registerable sight loss⁷.

Applying these estimates to the Hampshire population suggests that approximately:

- 500 people aged 18-64 are predicted to have a serious visual impairment.
- 8,000 people aged 65-74 are predicted to have a moderate or severe visual impairment.
- 15,500 people aged 75 and over are predicted to have a moderate or severe visual impairment⁸.

The Public Health Outcomes Framework includes an eye health indicator which will monitor three major causes of sight loss - glaucoma, age related macular degeneration (AMD) and diabetic retinopathy.

3.1 Certificate of Visual Impairment (CVI) and Registration

All Local Authorities have to maintain a register of blind people. Registration by the individual with a sight problem is voluntary, but becoming registered is a precondition for the receipt of certain financial benefits. The voluntary nature along with uncertainties about the regularity with which councils review and update their records, means that the reliability of register information is difficult to determine and so cannot be thought of as a

⁵ Kaye, A (2009): Lost and Found, RNIB.

⁶ The number of people in the UK with a Visual Impairment - the use of research evidence and official statistics to estimate and describe the size of the visually impaired population, N. Charles, RNIB (2006)

⁷ The prevalence of visual impairment in the UK: A review of the literature, Tate et al, RNIB (2005)

⁸ POPPI (Projecting Older People Population Information) and PANSI (Projecting Adult Needs and Service Information) databases, Institute of Public Care, Oxford Brookes University (accessed March 2012).

Sight Loss in Adults

definitive number of blind and partially sighted people. Registration is not a pre-requisite for social care support.

To become registered an individual must have a Certificate of Visual Impairment (CVI) issued by an Ophthalmologist (hospital eye doctor) which identifies one as being "Sight Impaired" or "Severely Sight Impaired". Sight Impaired (formally partially sighted) is the term used to identify some who has been assessed by an ophthalmologist as being "substantially and permanently handicapped by defective vision caused by congenital (present at birth) defect, illness or injury". Severely Sight Impaired (formally blind) is the term used to identify some who as been assessed by an ophthalmologist as being "so blind as to be unable to perform any work for which eyesight is essential."

In England in 2011 there were 298,000 people registered, 151,000 as sight impaired and 147,800 as severely sight impaired⁹.

In Hampshire during the same time period:

- 475 people aged between 0 and 64 had registered as sight impaired.
- 230 people aged between 65 and 74 had registered as sight impaired.
- 1,830 people aged 75 and over had registered as sight impaired.
- 575 people aged between 0 and 64 had registered as severely sight impaired.
- 240 people aged between 65 and 74 had registered as severely sight impaired.
- 1,665 people aged 75 and over had registered as severely sight impaired.¹⁰

3.2 Condition specific prevalence

3.2.1 Age Related Macular Degeneration (AMD)

Age related macular degeneration (AMD) is a painless condition that leads to a gradual loss of central vision as the macular loses function. The prevalence of AMD increases from 12.2% in people aged 55-64 years to 18.3% in those aged 65-74 years and 29.7% in people aged over 74¹¹. Recent studies suggest that as many as 40,000 people a year develop wet AMD with another 44,000 people a year diagnosed with dry AMD. The study also shows how the prevalence of AMD increases exponentially with age, roughly quadrupling every decade of life. Around one in two thousand people have AMD at 60 but by the age of 90 more than one in five will have it¹².

In Hampshire, it is estimated that approximately 5% of the population, or around 68,900 people, have AMD¹³.

3.2.2 Cataracts

Cataracts can be described as lens opacities which cause a gradual loss of vision. Cataracts are the main cause of impaired vision worldwide and linked with a range of predisposing conditions including nutritional deficiencies. There is consequently a wide range of cataract prevalence in the various epidemiological studies and therefore the

⁹ Registered Blind and Partially Sighted People Year ending 31 March 2011 England, The Health and Social Care Information Centre, (2011)

¹⁰ Registered Blind and Partially Sighted People Year ending 31 March 2011 England, The Health and Social Care Information Centre, (2011)

¹¹ Awareness of Age related Macular Degeneration and Associated Risk Factors, AMD Alliance, International Campaign Report (2005)

¹² The estimated prevalence and incidence of late stage age related macular degeneration in the UK, Christopher G Owen et al, British Journal of Ophthalmology (2011)

¹³ National Eye Health Epidemiological Model (NEHEM), www.eyehealthmodel.org.uk/MainApplication/ (accessed April 2012)

Sight Loss in Adults

estimate of the number of people in Hampshire with cataracts could be between 11,200 and 40,400¹⁴. However many of these people will not be living with their cataract but have received treatment.

3.2.3 Glaucoma

Glaucoma occurs when the drainage network within the eye becomes blocked. This leads to damage to the optic nerve with associated visual problems. The estimate of people in Hampshire with Glaucoma is approximately 11,200, although the estimated range is between 6,900 and 15,900. In addition there are a further 45,000 suspected Glaucoma cases and 25,400 incidences of ocular hypertension¹⁵.

3.2.4 Learning Disability¹⁶

It is estimated that there are about 1 million adults in the United Kingdom with a learning disability. People with learning disabilities are around 10 times more likely to have serious sight problems than other people and around 6 in 10 people with learning disabilities need glasses and often need support to get used to them. People with severe or profound learning disabilities are most likely to have sight problems. People with learning disabilities may not know they have a sight problem and may not be able to tell people. Many people think the person with a learning disability they know can see perfectly well.

4. Projected service use

4.1 National

Across the UK, the number of people living with a sight loss is expected increase to nearly 4 million people by 2050, an increase of 22%. The cost to the UK economy was approximately £6.5 billion in 2008, through direct costs to health and social care services and indirect costs such as informal care costs and work force losses. This figure is estimated to increase to £7.88 billion by 2013.

4.2 Local

The Hampshire population is ageing. The number of people aged over 65 is projected to increase from 267,000 people in 2013 (19.9% of the population) to 300,800 (21.6% of the population) by 2018. The number of people aged over 85 is projected to increase from 37,600 (2.8% of the population) in 2013 to 50,200 (3.6% of the population) by 2018. As the prevalence of eye health issues and conditions increases with health, it is likely that there will be more people in Hampshire, over the next 5 years, needing support for their eye health. Table 1 shows the estimated rise in numbers of people with visual impairment in Hampshire.

¹⁴ National Eye Health Epidemiological Model (NEHEM), www.eyehealthmodel.org.uk/MainApplication/ (accessed April 2012)

¹⁵ National Eye Health Epidemiological Model (NEHEM), www.eyehealthmodel.org.uk/MainApplication/ (accessed April 2012)

¹⁶ Estimates of the number of adults in the UK with learning disabilities and visual impairment - Research summary for the UK, SeeAbility & RNIB (2011)

Sight Loss in Adults

Table 1: estimated rise in number of people in Hampshire with visual impairment, 2013 to 2020¹⁷

	2013	2014	2015	2016	2018	2020
18-64 serious visual impairment	514	514	515	516	519	520
65-74 moderate or severe visual impairment	7,991	8,249	8,439	8,641	8,814	8,837
75+ moderate or severe visual impairment	15,413	15,872	16,306	16,653	17,782	19,245

The estimates show there could be a rise of just over 10% in people aged between 65 and 74 with a moderate or severe visual impairment and a rise of nearly 15% in people aged over 75 having a moderate or severe visual impairment.

5. Current service provision

Low vision services include optometric assessment, low vision therapy and rehabilitation. The services across the county are fragmented, with some areas of integrated good practice and others with problems in accessing basic optometric low vision assessment. There are a number of service providers in Hampshire, summarised below. Figure 1 outlines the sight loss care pathway in Hampshire.

5.1 Primary Care

Primary care (GPs) is the first point of contact for people who have a health issue. A GP will refer to either an optician / optometrist or to the local Eye Department to be seen by an Ophthalmologist. Likewise, it is not unusual for high street optometrists to ask the GP to refer a person to an Ophthalmologist or to refer directly themselves for a cataract opinion.

5.2 NHS Eye Services

Eye services are commissioned from acute hospitals to offer a comprehensive range of ophthalmic medical and surgical services (table 2). Consultant led services include facilities for the investigation and management of all ophthalmic conditions through a dedicated team of doctors, nurses, orthoptists, optometrists, and ancillary staff. Most outpatient clinics are based at the hospital where patients can access specialist support and diagnostic tools. Some hospitals also have consultant led clinics in the community, providing a valuable community service and reducing the need for travel and inconvenience to patients. Eye surgery will be undertaken in main hospitals. A very few eye conditions may benefit from a specialized assessment and treatment from a national centre of excellence.

5.3 Hampshire County Council Adult Services Sensory Team

www.hants.gov.uk/adult-services/visual-sensory-team

The Sensory Team Early Intervention Service operates across Hampshire and aims to provide timely interventions to people with sensory loss, including providing a 'listening ear'; advice and information about services and strategies that can reduce the negative impact of the sensory loss on a person's life; links to peer support and information groups; and signposting or referral on to a range of other specialist service providers. The sensory

¹⁷ POPPI (Projecting Older People Population Information) and PANSI (Projecting Adult Needs and Service Information) databases, Institute of Public Care, Oxford Brookes University (accessed March 2013).

Sight Loss in Adults

team can also provide a comprehensive holistic assessment in a person's home by a trained and experienced sensory specialist. If people are eligible this can lead to rehabilitation and enablement support, advice and information to assist a person to live safely with their sensory loss; access to a variety of assistive and environmental equipment; and reablement/rehabilitation programmes which teach people the skills they need to maintain the independent lifestyle of their choice.

5.4 Open Sight (www.opensight.org.uk)

Open Sight is the largest charitable organisation working with people who have, or who are experiencing the effects of sight loss across the whole of Hampshire. The organisation has 9 employees and 350 volunteers supporting the work, and has over 3,000 clients. Open Sight offers:

- Information and Guidance; benefits advice; qualified low vision equipment assessments/service; sighted guiding training; preventative talks; everyday living courses.
- Crisis Support; living with sight loss; benefits advice; everyday living aids/specialist equipment; qualified rehabilitation service with mobility guiding support provision.
- Long Term Support; social clubs; social activities/holidays; preventative talks; qualified low vision equipment assessments/service; everyday living aids; befriending service (Eastleigh Borough only).

5.5 Guide Dogs for the Blind (www.guidedogs.org.uk)

Guide Dogs has a Mobility Centre in Southampton from which the guide dog service and other mobility services such as long cane training and sighted guiding for adults, children and young people are coordinated and delivered. The organisations campaigns on issues that affect the free movement of blind and partially sighted people and offers advice in aspects of services, access and inclusion. Guide Dogs works with other organisations where this supports blind and partially sighted people's mobility aspirations. Services are provided throughout Hampshire.

5.6 The Macular Society (www.macularsociety.org)

The Macular Society is the only national UK charity dedicated to age related macular degeneration (AMD) and other macular conditions, including juvenile dystrophies. Work work falls into four main areas - information, support, research and campaigning. This includes information and advice services (information leaflets, telephone information and support and advocacy, local peers support groups and volunteer speakers); crisis support services (telephone professional counselling service, telephone advocacy service, telephone peer support (for those experiencing Charles Bonnet and for those about to undertake injection treatment) and eccentric viewing / steady eye training); and long term support services (local peer support groups, volunteering opportunities, EV trainers and speakers).

5.7 Action for Blind people (www.actionforblindpeople.org.uk)

Action for Blind People is a national charity with local reach, providing practical support to blind and partially sighted people of all ages. Action speaks louder for nearly 30,000 visually impaired people every year, placing their needs at the heart of everything. The organization supports people in many aspects of their lives and helps them to find the services and products they need to live independently. Action works with other expert organisations to draw on a range of resources and has a close relationship with RNIB.

Sight Loss in Adults

5.8 Royal National Institute for the Blind (www.rnib.org.uk)

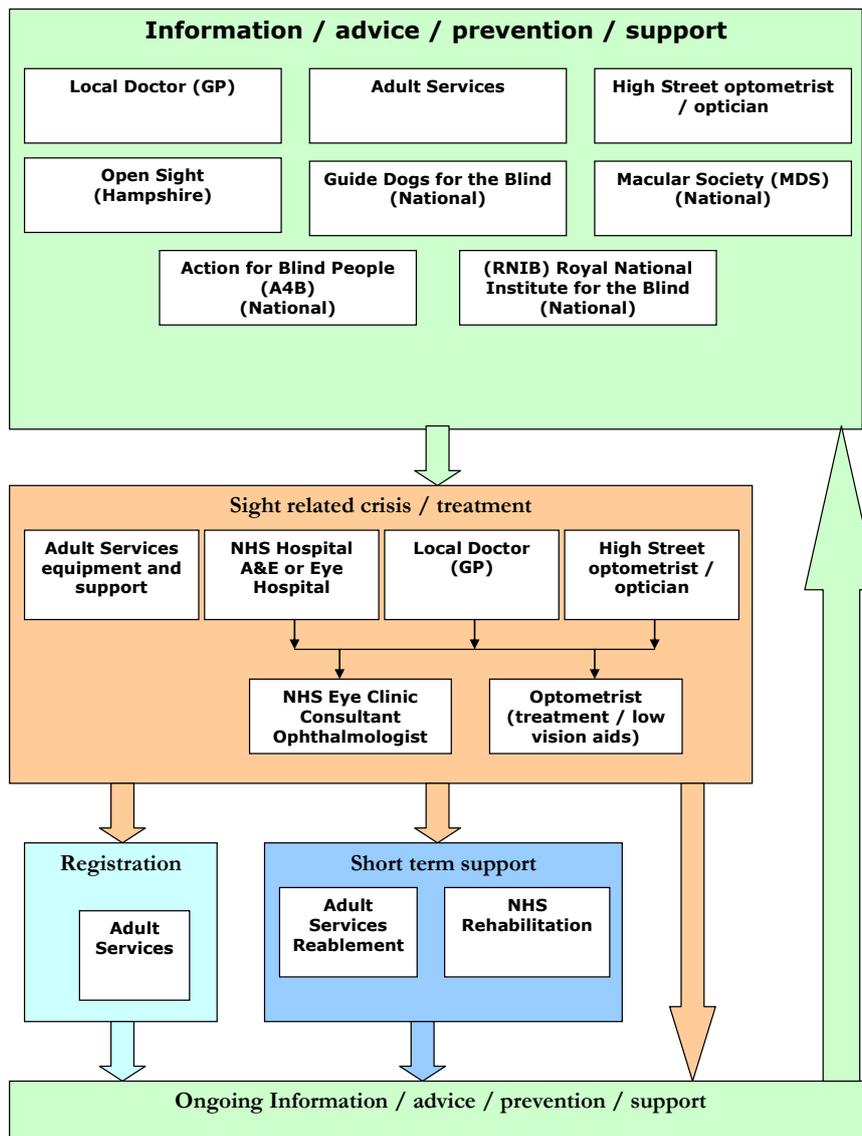
The Royal National Institute of Blind People (RNIB) is the leading charity offering information, support and advice to almost 2 million people with sight loss. RNIB is an organisation of blind and partially sighted people, passionately committed to ending the isolation of sight loss. The RNIB have practical ways to help people with a sight loss live with sight loss, can provide advice to help people with a sight loss travel, shop and manage their money and finances independently and can also provide advice on technology for blind and partially sighted people.

Table 2: hospitals with eye departments in Hampshire

Hospital
Portsmouth Hospitals NHS Trust, Portsmouth
Hampshire Hospital NHS Foundation Trust Basingstoke
Hampshire Hospital NHS Foundation Trust, Winchester
Frimley Park NHS Foundation Trust, Frimley
University Hospital of Southampton NHS Foundation Trust, Southampton

Figure 1: Sight loss pathway in Hampshire

Sight Loss in Adults



6. User view

The Vision 2020 UK (Hampshire) Board created a questionnaire that was designed to elicit an overview of what current service users felt about the current state of sensory loss services, to try to understand where gaps in the sensory pathway are. All organisations represented on the Board approached own service users during the first week of December 2012. The use of the questionnaire was completely voluntary, and was not designed to get a representative sample. The responses therefore are not representative of all service users, but are informative.

It should also be noted that due to the nature of their sight loss / eye health a number of people may have had the questions verbally and therefore confidentiality could be an issue for those individuals. Therefore organisation ensured that the questionnaire was only put forward after receipt of any services, and service users were able to decline to participate, and assured that this would not have any impact on the service they received now or in the future.

For a report on the survey please see <http://www.hants.gov.uk/sensoryjsna.doc>. The report also contains a copy of the questions that were asked and the breakdown of the 43 responses received.

Sight Loss in Adults

6.1 Survey results

43 service user responses were obtained from 6 different organisations, with 55% of all response received from one single organisation. Respondents had been diagnosed with 16 different eye conditions, with the primary one (34%) being some form of macular disease. 40% were male and 60% were female, with 59% of respondents below the age of 65 (40% were aged between 20 and 49). Out of the 41% of over 65's, 35% were over the age of 75. 93% of the respondents declared themselves as White English. Responses were received from people covering at least 24 different postcode areas.

Most of the respondents entered eye health service provision through an optician with the majority of the others through their GP. This is not unexpected as these are primary care services that are likely to be universally known as respondents generally suggested they knew who to call. What was good to note were that 4 or 5 respondents were referred from services other than primary health and social care, including Walk In centres, School and Health Visitors.

As the majority of first contacts are made through primary care it is essential that GPs and Opticians / Optometrists are fully engaged in eye health and eye condition service provision and development. The establishment of Clinical Commissioning Groups will facilitate this. It is also clear that people with concerns over their eye health prefer face to face contact rather than receiving information through more technological based sources.

The main message throughout the responses, as mentioned above, is around the lack of information received at first contact or once within the eye health system. Two thirds of respondents felt that they did not get the information they wanted at first contact, whether this be about their condition or the different types of support they could receive. It is also about how the information is delivered with large packs of information not found to be particularly helpful.

A majority of respondents were having at least annual eye checks before they made contact about a specific eye health problem, which is positive. Following the first contact nearly all respondents said they would be having an annual eye check. The importance of having regular eye checks is clearly being expressed at first contact.

Over half of respondents did not feel that they received the service and support that they wanted after first contact. Once in the eye health 'system' the majority of respondents received support from a number of different organisations, on average around 5 different services, although as previously noted this is not necessarily happening within a short time of diagnosis and it appears that most respondents, due to the reported lack of information available, are having to investigate, research and find their own most appropriate support.

When asked about which priority areas that respondents said needed to be focussed upon, three areas were clearly felt to be important. As well as 'Making sure I can receive the service close to where I live' and 'Ensuring the type of information and advice I need is available', a similar level of people also identified 'Making sure I can get a service promptly when I need it' as being important. These were seen, by respondents, to be far more important than receiving emotional support and making sure staff are helpful.

After first contact with an optician respondents said they would likely contact 'other' services rather than the optician again, but this is likely to be due to the first contact from

Sight Loss in Adults

the optician being to an eye clinic and respondents then feeling able to access further support and advice from the eye clinic. The numbers of people who would access their GP or Adult Services for further support remained consistent.

Conclusions from the survey

- The majority of respondents accessed the eye health system through an Optician or GP.
- The report suggests that one third of the population do not have an annual eye check, which is appropriate for most people.
- By far the biggest request from respondents was for better access to information, both about their condition and also about where they can go to find other support or services that might help them manage their condition.
- Also identified as priority areas for development were receiving services close to where they live, which for people with eye health problems is understandable, and making sure they receive a prompt service. It is clear from comments, that having an eye condition or deteriorating eye health is a major concern and that prompt, local and informative services are required.
- Once in the eye health system, people are tending to make use of multiple resources, but how they found out about these other support services and how well they are all interacting over an individuals eye health is not clear as not asked in this questionnaire.

6.2 Provider view¹⁸

6.2.1 The characteristics of the people in Hampshire who are most at risk of having sight problems

Generally providers of sight related services in Hampshire feel that it is the elderly who are most at risk of having sight problems, with the incidence of age-related eye conditions (Macular Degeneration, Cataract) increasing. There is also an increase in the number of people with comorbidity accessing sight related services, for example older people with sight loss that also have dementia and working adults with sight loss through diabetes. There is also the view that those individuals who smoke, have a poor diet, drink too much alcohol or are exposed to significant levels of sunshine are also likely to have a greater risk of developing sight problems. Another risk raised by providers of sight related services is around those individuals who for a range of reasons do not have regular and ongoing eye tests, whether that is because they live alone, have multiple disabilities and/or long term conditions, have untreatable eye conditions or are simply unaware, unable or unwilling to access eye tests.

6.2.2 The key issues / obstacles that people with a sight loss in Hampshire face when they try to access service and support for their sight problems

Providers of sight related services in Hampshire feel that one of the biggest issues is the public's and eye health professionals' lack of awareness of what support and services are actually available for people with a sight loss in the wider community, and how to access that support and service - for example when an eye health professional has to communicate that 'nothing can be done' for those individuals with the dry form of ARMD or when injections cease working for those with wet AMD. It was also felt that many individuals may lack an understanding of the health factors relating to eye sight, which options of care and rehabilitation may prove helpful to them, and about benefits associated with CVI registration. This could be due to the way that Health, Social Care and third

¹⁸ All stakeholders of the Hampshire Vision Partnership Group (Vision 2020) were asked to respond, with views received from the Local Optometric Committee, The Macular Society, Open Sight, Hampshire County Council Adult Services Sensory Team and SHIP PCT.

Sight Loss in Adults

sector (charities, voluntary groups and other not for profit organisations) organisations let people know about ('market') the support and services they offer, or could be due to how and where information on sight loss is made available (for example are there too few Eye Clinic Liaison Officers to support signposting and access to services?). It may also be due to the way that the information is shared and passed on, particularly by eye health professionals.

Providers of sight related services in Hampshire also felt there was a lack of co-ordination between different parts of the 'sight loss pathway' (the way that the range of services and support for people with sight loss link together) across Hampshire. For example, where individuals referred by one service to other appropriate services may face long waits for an appointment (which may cause their eye condition to worsen) or when services do not let each other know what support they have provided or are providing to an individual, making it difficult for either organisation to 'join up' the care and support being provided to enable them to appropriately support the individual in the future. This may be down to information sharing difficulties between services or other barriers caused by either the system or self inflicted by the services themselves. It is suggested that 'one stop shops', consisting of integrated ophthalmic, low vision and rehabilitation services be developed. This may support the sharing of knowledge and best practice, for example improving what is seen to be a lack of knowledge, skills and capacity among eye health, social care and third sector workers in the rehabilitative techniques of Eccentric Viewing and SES training

Another issue that individuals face is that there appears too few opportunities for individuals to have a low vision assessment with patchy and poor availability of low vision aids within Hampshire. There were also issues raised around the Certification as Vision Impaired (CVI) process, which is seen as a trigger for other services, however delays in the system processing the CVI may mean the timeliness and quality of services received by the individual are reduced.

6.2 3 Making it easier for people in Hampshire to receive the services and support that they need for their sight problems when they need it

It was felt by sight related service providers in Hampshire that a key way for people in Hampshire to have better and easier access to services for their sight problems was to develop better care and support care within the community. This could include integrating Ophthalmic, Low Vision and rehabilitation support into one stop shop services within the community. It was felt, though, that this would likely require a better use of or a further investment in baseline resources, i.e. increased funding, to develop these community based services.

It was also suggested that there was a requirement to improve communication about current services on offer to increase the awareness of professionals and the general public those services. This may include up-skilling acute and community based eye health and social care professionals so that they have a better understanding of all community services available and actively promoting the services and support offered by health, social care and other organisations in an accessible format. Individuals themselves (and their families) also have responsibility in the sight loss pathway and therefore it is vital that good quality, easy-to-access information plays a vital role in empowering individuals to make informed decisions. This could be provided, for example, through accessing online information, but this may require support for individuals with sight loss to build ICT skills and obtain appropriate equipment.

Sight Loss in Adults

A way to provide the information might be through a clearly published pathway showing how to access and find a range of different sight related services. This could be achieved by all organisations within the pathway providing a standardised information set about their services within a single booklet / information source. This would mean that at whatever point the individual comes into the pathway, they receive quality information about all services available to them. This booklet could also contain information about what the individual needs to do, and when.

6.2.4 Identification of gaps in the current range of services being provided for people with sight loss in Hampshire

Following on from the comments above, sight loss service providers felt the gaps in the current range of sight loss services in Hampshire were as follows:

- There are limited community based low vision aid services which mean that comprehensive and geographically equitable access to Low Vision Assessments and Low Vision Aids is not available.
- Lack of a joined up follow-up process once diagnosis has been made, compounded by a lack of advice and information for those people who have just been diagnosed with a sight condition to prevent their condition worsening and to make them aware of what support and service is available to them.
- An integrated and joined up approach between Ophthalmic, Low Vision and Rehabilitation Services to ensure gaps between services are reduced.
- Access to, and sharing of, general and more specialist knowledge and training, for example Eccentric Viewing training, to ensure that there is an understanding of what support is available and that appropriate referrals can be made between organisations to ensure individuals do not receive gaps in their service provision.
- Access to specialist IT equipment for people living with sight loss. If an individual can be trained to use a PC with magnification and/or speech output and a talking scanner (for scanning letters, bills onto the computer) the individual can remain independent with a lot of daily living tasks, for example managing finances, shopping online or keeping in touch with family/friends.
- Access to emotional support/counselling services. It is clear that a lot of people cope immensely well with deterioration of vision. However, for some, professional support could significantly increase their chances (and speed) of regaining independence.

6.2.5 Improving the wellbeing of people with a sight loss in Hampshire

Providers of sight related services suggested:

- Information, advice and sign-posting service at point of diagnosis to enable the client to access the right support for their condition.
- Providing a community based service closer to the patient.
- Providing individuals with emotional, practical and financial support if they are to remain healthy and well.
- Providing a decent range of Low vision aids and visual rehabilitation training.
- Seamless communication and information sharing among the organisations within the sight loss pathway, with a countywide agreement (protocol) on when, what, how and with whom to share.

7. Recommendations

It is recommended that Acute Trusts, Clinical Commissioning Groups, Optometrists, Adult Social Care, third sector eye health organisations and other stakeholders work together to deliver the following:

Sight Loss in Adults

7.1 Awareness raising

The RNIB estimate that over 50% of sight loss can be avoided and therefore it is recommended that there is a greater emphasis on prevention and early interventions. The links between sight loss and health factors such as diabetes and smoking, age and BMI groups need to be emphasised through public health, primary care and all organisations involved in eye health to improve prevention of sight loss due to these health factors. In addition there is a need for greater public awareness generally around maintaining their eye health. Better information provision and signposting around eye health needs to happen in primary care, where it is most likely that people will first raise concerns, or have concerns raised, about their eye health.

7.2 Prevention and early intervention

With respect to early intervention there needs to be increased support to develop a coordinated Low Vision pathway with an adequate and appropriate availability of Low Vision Assessments (LVA) and a co-ordinated county wide standardised provision of services, support (including training in Eccentric Viewing and Steady Eye) equipment and aids and training.

Evidence of good practice: Gateshead (Sight Services) model.

7.3 'Post diagnosis' support

To develop an appropriate 'post diagnosis' package for patients who have recently been diagnosed with an eye condition, either in a hospital or in a community setting, or those who have been admitted to hospital for an injury that may have been compounded by their eye condition. This should include making sure people are made aware of the opportunity for Certificate of Visual Impairment (CVI) registration and the benefits registration can provide and making sure that they receive a comprehensive explanation of available support and services. This could be done at point of diagnosis, but as this may not be an appropriate time for some people, there will need to be provision to follow up later. This could best be done through having dedicated eye health support staff (Eye Clinic Liaison Officers (ECLOs)) within eye clinics and other community settings who could raise awareness of eye health throughout all departments in hospitals or their community, and improve links between eye clinics and other hospital departments, social services and third sector agencies. It is anticipated that this early intervention will support and maximise the opportunities for re-enablement and helps to prevent readmission into the health care system as a result of people being unable to manage their eye condition.

Evidence of good practice: ECLO service at Moorfields Hospital, London and Southampton Hospital.

7.4 Information provision

Combine and coordinate local and national sources of information and support, into a single 'one-stop-shop' system / access point for all individual, statutory and third sector queries. The link(s) to the information sources would be shared by ECLOs at the point of diagnosis, as well as being shared with, and advertised in, GP surgeries, Ophthalmic Departments, Optometrist services and other stakeholders. This could provide information to people who have an eye health issue and have not yet been in contact with eye health services, people who have been recently diagnosed at an eye clinic with further information on their eye condition, advice or about registration and/or family members who want to help but do not know how to easily access information. This could be funded by statutory or partnership funding.

Sight Loss in Adults

Evidence of good practice: South West Consortium (Guide Dogs, Devon Insight, Action for Blind People, Sense) who run a helpline of this nature.

7.5 Joint agency sight-loss pathway

Develop and adopt a cross county statutory and third sector sight-loss pathway, to optimise partnership working and smooth transitions between services. As a result of the joint nature of the pathway, people with complex needs, in particular vulnerable groups such as young people of transitional age and the elderly, are more likely to need to accessed the range of agencies. The availability of a joint pathway adopted by eye clinics, GPs and Opticians means that they are more likely to cross-refer someone whose primary condition may not be sight loss, but whose quality of life and readmission rate may be improved by access to eye health services. The UK Vision Strategy Group suggests a pathway built around:

- Preventative work
- Early intervention to address presenting need
- Visual Impairment rehabilitation
- Social Care and other community based services

Evidence of good practice: [RNIB Quick Wins report for Commissioners](#); [UK Vision Strategy Adult UK Sight Loss pathway](#)

7.6 Information sharing

Early notification to third sector agencies could be enabled by sharing the list of patients issued with a CVI. The patient would consent to their information being shared, and would be contacted by the relevant sight loss agency in their area. Agencies could request the information on a weekly/monthly basis. This means third sector agencies can increase access to service users who choose not to register, and would by-pass the 3- 6 weeks+ waiting list for registration assessment.

Evidence of good practice: There are some 3rd sector organisations ([Kent Association for the Blind](#)) that hold the CVI list, and whilst this is not recommended here, it does appear that the opportunity for 3rd sector organisations having this information can enable better access to information.