

WEST SUSSEX HEALTH NEEDS ASSESSMENT

Visual Impairment (Adults) November 2021

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This is a summary of sight impairment prevalence, the sight loss pathway and the provision of low vision services.

This is centred on the non-clinical aspects of provision; acute and specialist services are currently (2021) subject to a review by SHCP.

It is important that all elements within a care pathway, whether relating to a person's clinical or social needs are viewed together to ensure the range of needs and concerns are addressed. To this end an initial discussion has taken place with NHS Commissioners.

Acknowledgements

Thank you for the support from 4Sight, RNIB, NHS and WSCC staff in the provision of information.

Thank you to the SHCP Commissioning Leads for ensuring that work derived from the needs assessment can help inform service re-design.

A specific thanks to West Sussex Healthwatch, and of note Cheryl Berry, who chaired and led much of the engagement work. This was a difficult time to progress engagement and without her huge endeavours and efforts the input, views and voice of local residents would not have been captured. Thank you.

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This executive summary is centred on sight impairment, relating to adults.

Further reports are needed in relation to hearing impairment, dual sensory impairment and a specific report relating to children and young people.

Executive Summary

In West Sussex, there are an estimated 34,000 people living with sight loss, with an estimated 4,700 people who are blind.

Sight loss and hearing loss are strongly associated with age. As the population of West Sussex increases and the proportion of older people increases, so will the prevalence of sensory impairment. To provide a sense of the scale of change, at present there are an estimated 6,300 people aged 75 who have a registrable eye condition; using population projections, an increase of almost 30% is estimated within the next 10 years.

In addition to age, we know that some groups have a higher risk of sight loss, including smokers, some ethnic groups and people with a learning disability, and that there are links to other conditions such as stroke, diabetes and dementia.

There are four main eye conditions: age-macular degeneration (AMD), glaucoma, cataracts and diabetic eye disease. We know that many people in the community would benefit and avoid sight loss by early diagnosis and timely treatment. Some eye conditions, such as glaucoma, are asymptomatic in early stage. This means that regular eye tests are vital and should be widely promoted.

Once a sight loss diagnosis has been made, considerable support is required. The UK Adult Sight Loss Pathway¹ outlines the variety of organisations and sectors who can support someone to adjust, practically and emotionally. It is important that sight impairment is considered in all aspects of health and wellbeing, including support to remain physically fit, access to all health care, community services and facilities, and adaptations to maintain independence and employment for working age adults.

¹ Adult UK Eye Health and Sight Loss pathway. 2015. VISION 2020 UK

Challenges Identified and Recommendations

1. Sensory impairment is a major contributor to the overall burden of ill health in the local population. Sight and hearing loss can have a considerable impact on the quality of life and the ability of people to live independently. It is estimated that 50% of sight loss is avoidable.

(i) The needs of people affected by sight and/or hearing impairment should be considered, and addressed, by *all* services.

2. It is important to promote good eye health and not just focus on poor health, services and specific conditions. The role of modifiable risk factors, and the importance of eye tests and screening, should be key public health messages. Many of the modifiable risk factors, such as smoking, diet and increased physical activity, are central to overall health and wellbeing.

(i) The importance of eye tests should be promoted amongst the wider population, with targeted promotion in relation to higher risk groups.

(ii) Eye health should also be included in existing public health campaigns such as winter health.

3. Older People - The prevalence of sight loss is age-related, and with the proportion of people aged 65 and over in West Sussex increasing, the number of people with sight and hearing impairment will increase, including those with dual impairment. Services will need to expand and be tailored to meet the needs of an older population.

As a speciality ophthalmology is the largest volume health services, accounting, nationally, for over 9% of all outpatient attendances. The scale of activity will increase with an ageing population.

(i) Services need to be accessible: in respect of the design of facilities this means they should be suitable for people with reduced mobility and have accessible toilets; their location should take into account public transport, and parking;

information provided should be tailored (and provided in many accessible formats) to promote a better understanding by the patient and families/carers.

(ii) The needs of people within care homes should be addressed within commissioning and strategic plans.

4. While a care pathway can often be described, from a service perspective, as a linear process, it is important that services encourage people to engage whenever they are ready, ready to take on board information and support. In relation to sight loss, people may feel overwhelmed at the point of a diagnosis, and sometimes may not understand support available or understand the value of getting an impairment registered.

(i) Information should be available in different formats and at different times, to encourage people to engage with services and support beyond initial diagnoses or their first contact with services.

5. Existing Pathway in West Sussex – The access to low vision services differs across the county, depending on how and where people first access services. People in Mid Sussex were particularly impacted by the removal of low vision services at Princess Royal Hospital in Haywards Heath. While people can still access services elsewhere this may incur fees. The impact of the removal of services at Princess Royal was subject to a report to the West Sussex Health and Adult Social Care Select Committee in June 2019.

(i) An update on the impact of the removal of services at Princess Royal, and the overall equity of access to low vision services across the county, is required.

6. Co-morbidities - There are some strong overlaps with other conditions, including diabetes, stroke and dementia.

(i) Care pathways of these conditions need to consider how people with sight impairment are supported.

- (ii) There also needs to be strong links to other programmes, such as falls prevention programmes, where sight impairment increases risk.**

7. People who have a learning disability are more likely to be affected by sight impairment. Their access to assessment and screening, take-up of treatment and outcomes should be monitored to address any issues of equity.

- (i) The take-up of sight tests should be monitored as part of annual learning disability health checks carried out by GP practices.**

- (ii) Easy-to-read information should be provided to support an understanding of the importance of eye tests and eye conditions.**

8. The adult sight loss pathway outlines a range of providers in the public, private and voluntary sectors, as such it is a complex pathway and system. At a strategic level this requires commissioners to clearly articulate services along the whole pathway and system, working at a population level to identify gaps in services and address any inequities. To navigate this pathway, it is important that there is good communication between organisations, and good information for the patient, so people know what to expect, when, and from whom. There are some practical steps which may support a more population focussed and system-level approach:

- (i) A performance and outcomes framework across the system should be explored. The work of the Clinical Council for Eye Health Commissioning (CCEHC), including the System and Assurance Framework for Eye-health (SAFE) provide tools to support do this. This includes a proposed set of indicators to monitor eye health and care.**
- (ii) Commissioners from across the pathway and system should jointly publish eye health indicators on an annual basis.**

9. In relation to the pathway and COVID-19:

There is increasing demand across the pathway. Prior to COVID-19, analysis of Hospital Episode Statistics (referred to as HES data) showed a 10% growth in elected admissions between 2017/18 and 2019/20.

Data from NHS Digital show that the waiting times for admitted and non-admitted ophthalmology has increased nationally and locally over the last year. This is not surprising given the impact of COVID-19 and recovery will need to be monitored. The local picture is somewhat complicated with the merger of three CCGs to a single West Sussex CCG.

Early detection is a priority. Regular eye tests are an important route to detecting problems at an early stage. Information relating to the take-up of eye tests was not available at a local level; and nationally data are poor. Assessing equitable take up is not possible.

(i) The impact of COVID-19 may have exacerbated any existing inequities, including take-up of eye tests within more deprived areas and by people from different ethnic groups known to be at higher risk of sight loss. Health equity audits should be undertaken where possible but may be hindered by a lack of data.

10. Finally, most care is self-care, by the individual, often supported by carers, families and communities. Professionals along the sight loss pathway have a responsibility to support people in their understanding of their condition, their treatment, and the services available. In turn the knowledge and experience of patients, and carers and advocate groups/organisations, is needed to shape services and improve outcomes.

(i) Given the complexity of the sight loss pathway, any redesign requires good, on-going engagement with organisations, patients and carers.

Sensory Impairment as a Public Health Issue

In terms of overall public health, it is important to recognise that visual and hearing impairment are large contributors to the overall burden of ill health in West Sussex, particularly for people aged 70 years and over. The Global Burden of Disease Study² ranks, for each country and for areas within the UK, the causes of death and the causes of ill health and disability. This recognises that many conditions may not kill you but can have a considerable impact on health, wellbeing and the quality of life. In 2017, for people aged 70 years or over in West Sussex, age-related hearing loss was ranked 3rd as a cause of ill health and disability, after low back pain and diabetes, and blindness and low vision ranked 11th.

Sight impairment and blindness should be regarded as a major public health issue:

- Sight loss affects a large number of people within the West Sussex population
- Sight loss has a major impact on the everyday life and wellbeing of individuals
- As a problem it is increasing, and is projected to increase over the next 30 years
- It places a considerable economic burden on individuals, families, communities and the health and social care system
- Some sight loss is preventable if diagnosed early and treated in a timely manner and there are evidence-based interventions available.

Using RNIB estimates³ for West Sussex, direct costs (health and social care services, prescribing etc), indirect costs (such as employment loss, informal care) and the wider economic impact (reduction in the quality and length of life) are as follows:

- Direct costs = £48m
- Indirect costs = £90.8m
- Wider economic impact = £319m

² Global Burden of Disease Study 2019 Seattle, Institute for Health Metrics and Evaluation (IHME), 2021.

³ Estimates taken from the RNIB Sight Loss Tool

West Sussex – Background Context

Population

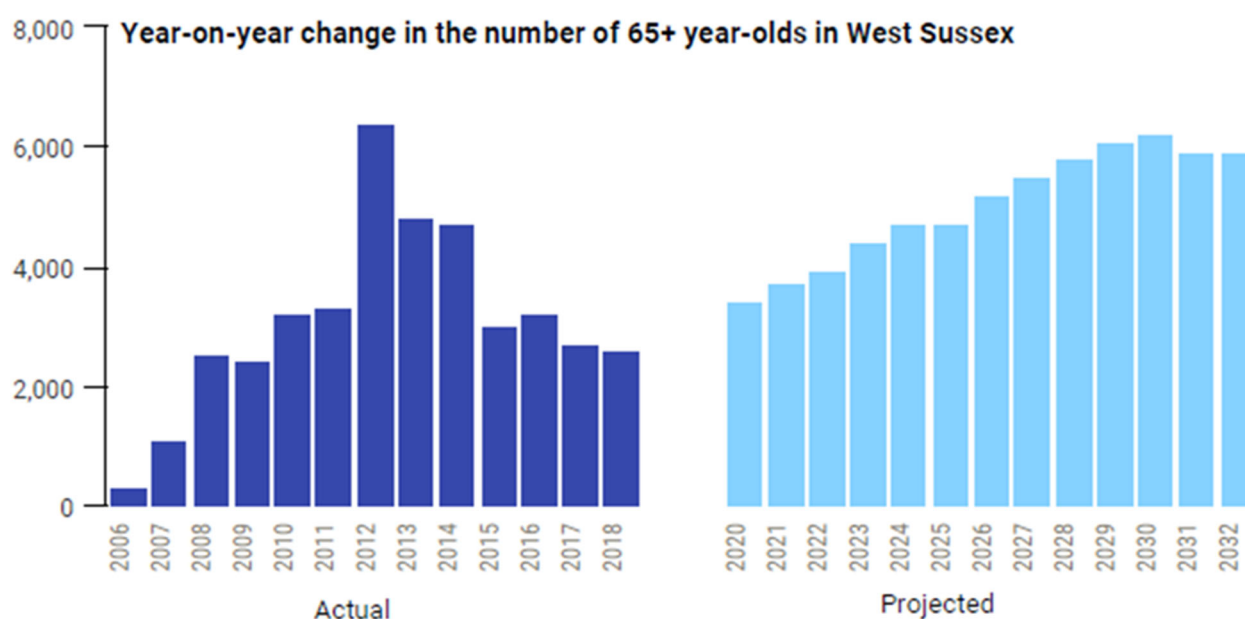
The 2020 ONS mid-year population estimates⁴ for West Sussex show that the county is home to more than 863,000 residents. Projections⁵, based on recent trends, indicate that by 2028 the population in West Sussex will increase to more than 925,900, and by 2038, the resident population of West Sussex is expected to reach 976,900.

West Sussex has an older age structure compared to England overall, with a greater proportion of older people and a smaller proportion of young adults. In 2018, over one in five residents (22%) in West Sussex was aged 65 years or over. The number of older people is expected to increase over time at a greater rate than the increase in overall population numbers (all ages).

Over the next decade, the number of people aged 65+ is expected to increase to one in four (26%) and by 2038, 30% (almost one in three) residents will be aged 65 and over. This is much higher than national estimates (18% in 2018, 21% in 2028 and 24% in 2038).

The pace of change will also increase, with the average year-on-year change increasing from 3,600 in the last 10 years to over 4,700 in the next 10 years.

Projected Year-on-Year Change in 65+ Year Olds 2020 to 2032



⁴ <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates>

⁵ <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections>

Assets and Overall Health and Wellbeing

West Sussex is a county rich in natural, cultural, and historical assets including seaside resorts, market towns, villages, theatres, historical sites, and the South Downs National Park. Towns in the county are frequently featured as top places people choose to live, retire, or work.

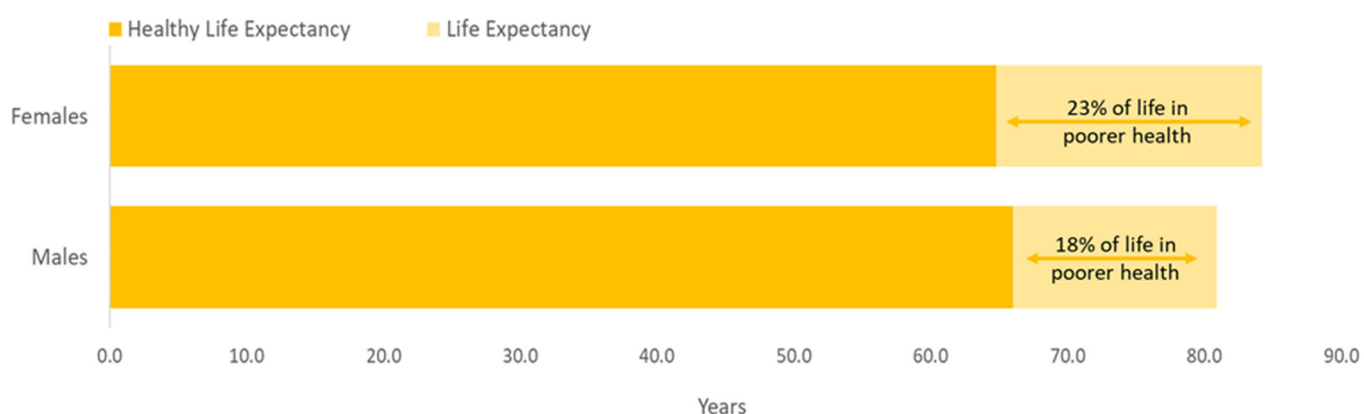
West Sussex has a large number and variety of organisations, groups and associations that are fundamental in the delivery of services that support health and wellbeing; these support individuals, families and communities, and enhance the vibrancy and quality of life in the county.

There are over 325 schools; over 80 GP practices grouped into 20 Primary Care Networks (PCN); 160 community pharmacies; hospitals with A&E departments at Chichester and Worthing, and additional NHS hospital sites across the county; over 30 libraries; and numerous museums, galleries, theatres and historic properties.

Male and female life expectancy has increased over time and remains above regional and national levels. It is currently 80.9 years for men and 84.2 years for women (2017-19).

In West Sussex, while overall life expectancy is significantly higher than England, healthy life expectancy (HLE) for women has fallen and is no longer significantly higher than England. In 2017-2019, HLE for women remains below 65 years, at 64.8 years, and is below that of men (66.0 years). The outcome of a stalling/falling healthy life expectancy is that a greater proportion of life is being spent in poorer health. For men, on average, 18% of life is spent in poor health; for women, it is 23%.

West Sussex Healthy Life Expectancy and Life Expectancy (2017-19)



This means that the period in which people are likely to require health and care support will increase.

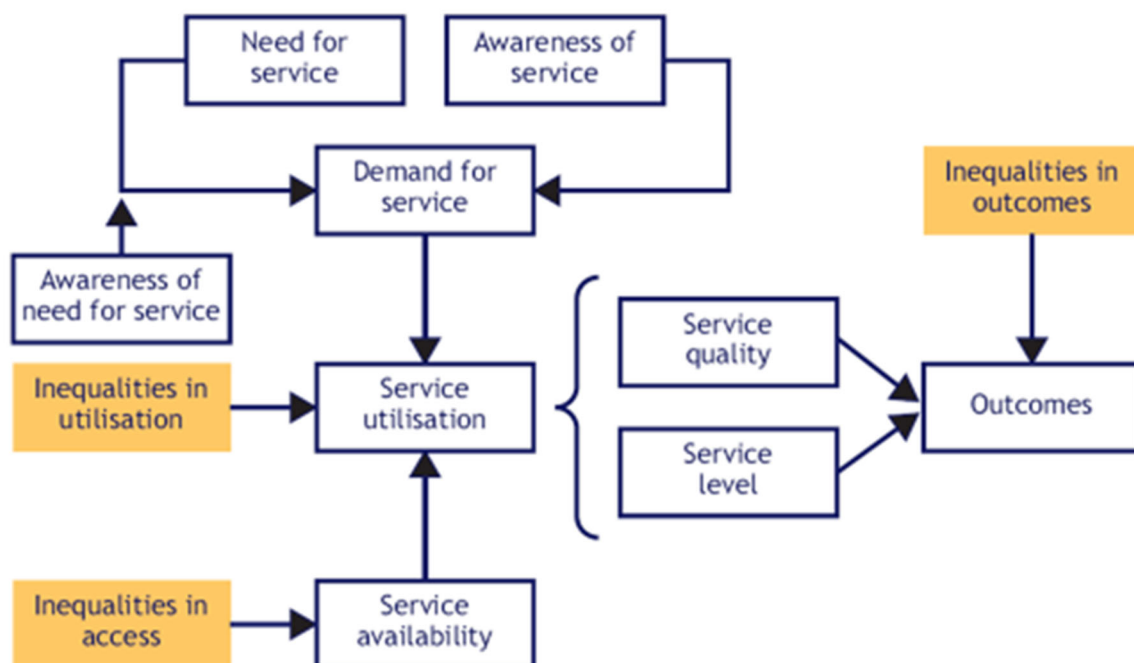
Protected Characteristics and Groups at Higher Risk of Poor Health Outcomes

Different groups in the population are at higher risk of poorer health outcomes.

To address inequalities, it is important to consider where within a system, or pathway, that issues need to be tackled. This means commissioners need to be aware of who may be at greater risk of having or developing sight loss, (for example, some ethnic groups have a higher risk of developing diabetes), but also where a system may have barriers to those seeking help, for example if people on lower incomes perceive sight tests to be expensive, they may not come forward to have their eyes tested.

Addressing Inequalities within a System

Inequalities in Service Access, Take Up and Outcomes



Source : London School of Economics and Political Science

The Equality Act 2010 outlines protected characteristics: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. A summary of these in West Sussex is shown overleaf.

In respect to protected characteristics, public organisations must have *“due regard to the need to: eliminate unlawful discrimination, harassment and victimisation [and to] advance equality of opportunity between people who share a relevant protected characteristic and people who do not share it”*. This is not just a legal duty; it is important that people who plan and deliver services work to address health inequalities and promote equity, including equity in how people have access to knowledge and information about their own health, how people access services and have on-going treatment, and how they experience a service and the outcomes from it. Visual impairment falls within the disability characteristic and there are also some crossovers with other characteristics.

In summary the following should be considered:

Age and Sex

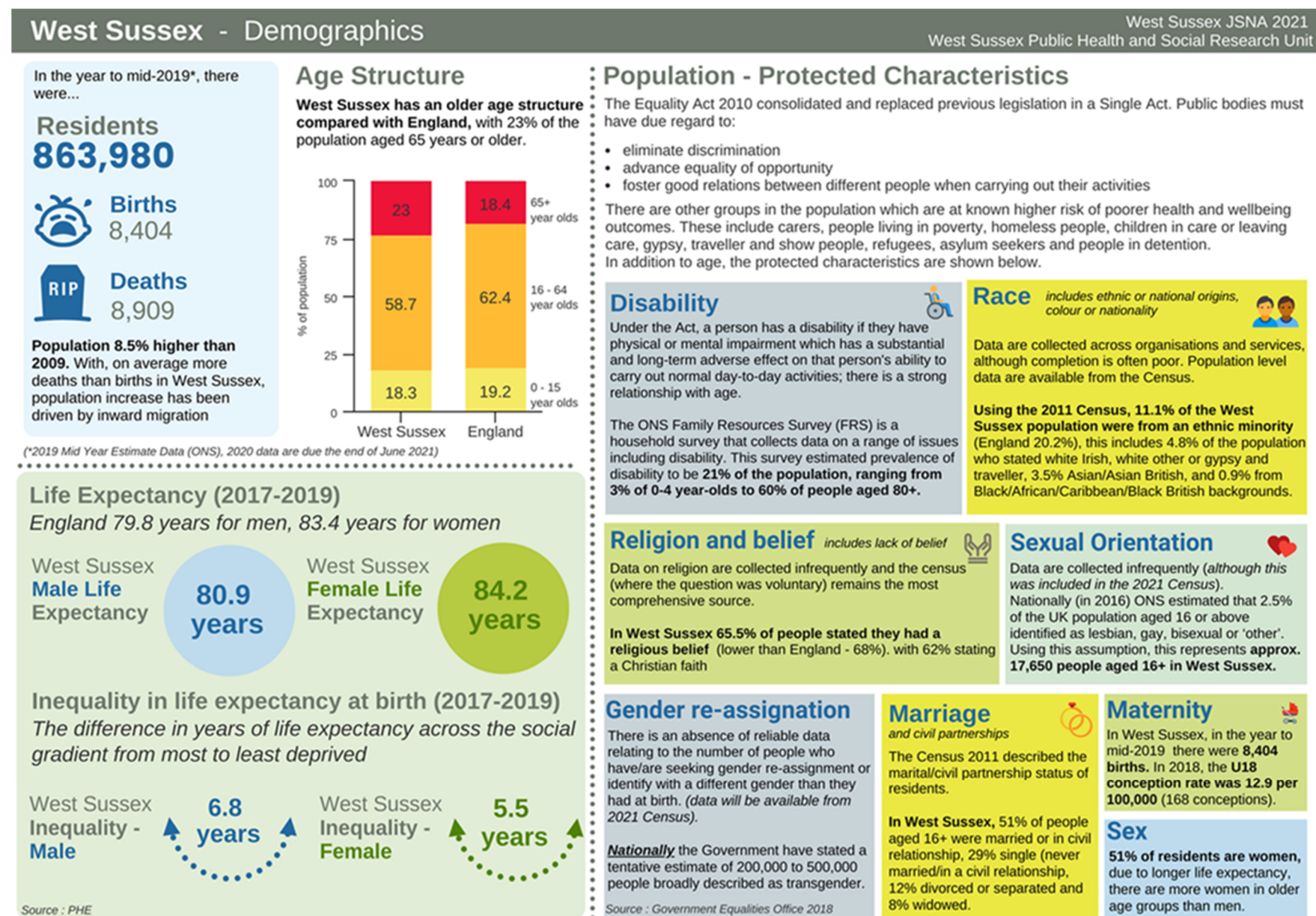
- There is a strong association with age and sight impairment.
- As women have a longer life expectancy on average, a higher proportion of people with sight loss are women.

Ethnicity

There are differences between ethnic groups in the risks of sight impairment caused by specific conditions:

- Black people have a greater risk of developing age-related macular degeneration (AMD) compared to white people in younger age groups, whereas white people have greater risk of developing AMD later in life.
- Black people have more than double the risk of other ethnic groups of developing glaucoma.
- Asian people are at lower risk than white people of AMD.
- With 20% of its population belonging to an ethnic minority, Crawley is the only district in West Sussex in which ethnicity is a potentially significant factor in visual impairment.

Protected Characteristics in West Sussex



Co-morbidities

Diabetes

Diabetic retinopathy is a complication of diabetes and occurs when changes in blood sugar level affect retinal blood vessels. The risk of diabetic retinopathy increases with age and is also higher when blood sugar levels are less controlled and there is higher blood pressure. Untreated it can lead to sight loss and blindness.

In West Sussex in 2019/2020, over 54,000 people were on GP diabetes registers.

Stroke

Visual problems are common amongst people who have had a stroke, with estimates between 60-70% of people experiencing problems, including problems with eye movement and alignment, visual field, and perception. In addition, a stroke may impact the ability to read and/or write.

In West Sussex, over 19,000 stroke survivors are on GP registers.

People who have a learning disability

It is estimated that one in three people who have a learning disability have a sight impairment or sight loss, and adults with a learning disability are up to 10 times more likely to be partially sighted or blind⁶. While the prevalence of sensory impairment is higher amongst adults with a learning disability, there is evidence⁷ that they are less likely to take up services and treatment or do so at an early point. It is therefore important that any barriers, such as an understanding that there may be an issue, availability of tailored information, and in getting early tests and sustaining on-going treatment, are addressed.

In West Sussex, there are:

- an estimated 16,000 people aged 18 years or over with a learning disability, with approximately 3,300 adults with a moderate or severe learning disability.
- 4,900 people on GP learning disability registers
- an estimated 300 adults aged 18 years or over with Down's Syndrome.

⁶ Emerson and Robertson, The Estimated Prevalence of Visual Impairment among People with Learning Disabilities in the UK (2011) <https://www.rnib.org.uk/sites/default/files/Emerson%20report.pdf>

⁷ Eye care and people with learning disabilities: making reasonable adjustments Department of Health (2020)

People with dementia

Dementia is also strongly related to age, meaning that many people who experience sight loss will also experience dementia. RNIB estimate that, at a national level, 123,000 people have both dementia and serious sight loss. This can increase the sense of isolation, confusion and anxiety, increase the risk of falls, and impact the ability to adapt (for example, being able to use new equipment or aids).

In West Sussex, it is estimated⁸ that there are over 15,000 people aged 65+ years living with dementia, and a further 250 people below the age of 65 with early onset dementia.

Approximately 9,300 people are on West Sussex GP dementia registers.

Other Groups at Risk of Poorer Health Outcomes

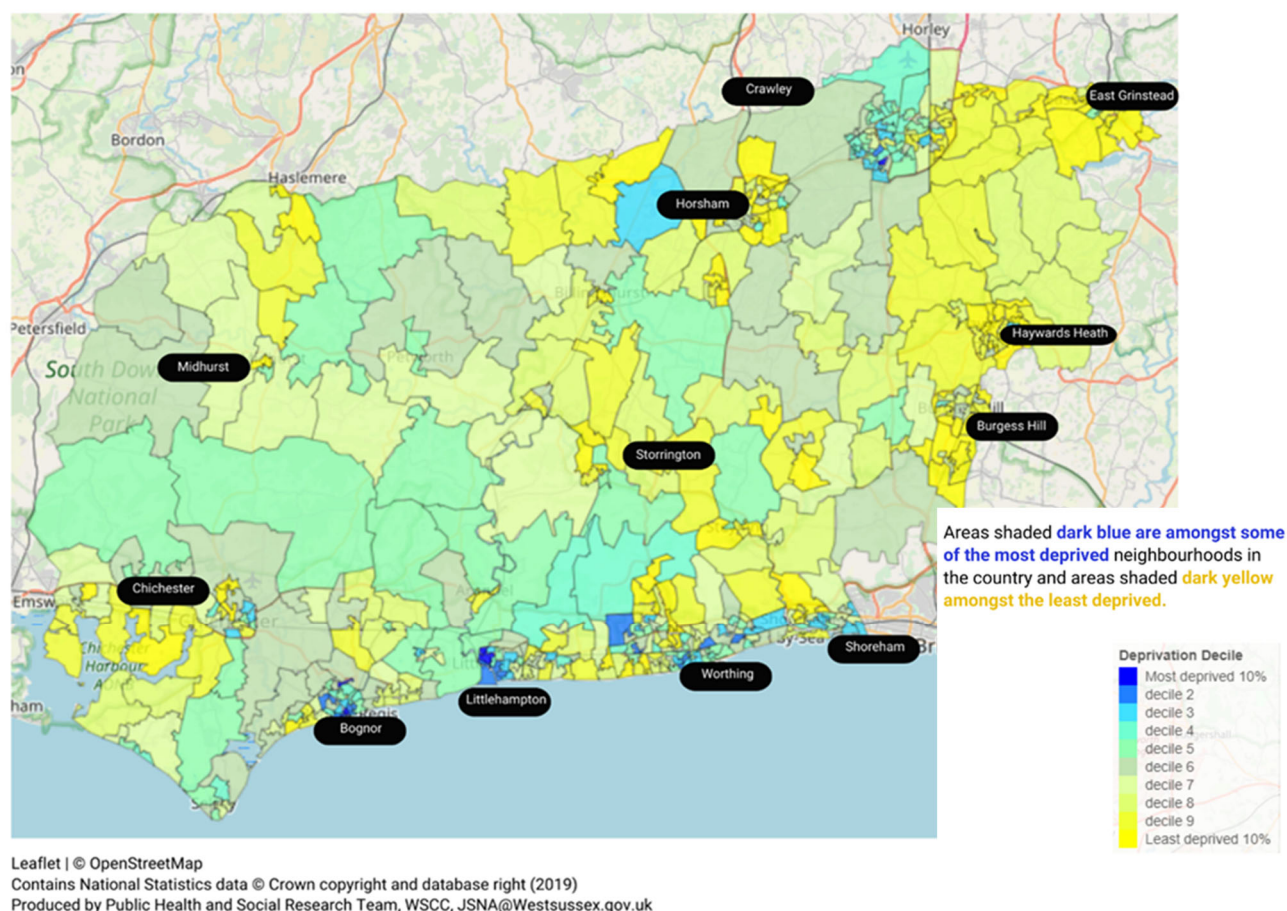
We also know that other groups such as carers, people living in poverty, homeless etc may be at higher risk of poorer health outcomes.

Deprivation

The "average" in West Sussex masks considerable inequality, and differences between areas and between different groups within the population. Some neighbourhoods in Arun and Crawley now rank amongst the poorest 10% of all areas in England, and there remain considerable differences between the life expectancy of the wider population and people with mental health problems and those with disabilities, including learning disabilities. Men in the least deprived neighbourhoods are estimated to live around six years longer than those in the most deprived neighbourhoods. For women, the gap is even larger (estimated to be 7.2 years).

⁸ Estimate taken from the Institute of Public Care's Projecting Older People Population Information Tool
<https://www.poppi.org.uk/>

Deprivation in West Sussex



Working Age Population in Receipt of Benefits

Personal Independence Payment (PIP) is a working age benefit, which replaced Disability Living Allowance (DLA), although many people have remained on DLA and are waiting for re-assessment. **In West Sussex, it is estimated⁹ that approximately 800 blind and partially sighted people are claiming either Personal Independence Payment (PIP) or Disabled Living Allowance (DLA).** RNIB estimated that in March 2020 approximately 16% of working age people on DLA were still waiting to be moved to PIP

PIP has two rates, depending on whether the ability to carry out daily living or mobility activities are considered limited (where PIP is paid at the standard rate) or severely limited (where PIP is paid at an enhanced rate). The benefit has two components: one for daily living costs and one for mobility costs.

⁹ Estimate taken from the RNIB Sight Loss Tool for Local Authorities

In April 2021, 433 people in West Sussex were in receipt of PIP with the main condition mapped to ICD codes of H00 – H59 (Diseases of the Eye and Adnexa).

People in Receipt of Personal Independence Payment (PIP) April 2021

Area	Diseases of the Eye and Adnexa (H00 - H59)
Adur	34
Arun	84
Chichester	54
Crawley	70
Horsham	50
Mid Sussex	67
Worthing	79
West Sussex	433

Source: DWP

For new claimants of state pension age or above, Attendance Allowance is claimed, rather than PIP.

Behaviours - Smoking Rates

Smoking is a modifiable risk factor to eye health. West Sussex has a relatively low smoking rate compared with many other areas. However, even with an encouraging fall in the prevalence over recent years, it remains the case that 1 in 10 adults say that they currently smoke, and this is higher amongst more deprived groups and areas, with over 15% of adults in Crawley being current smokers. Data collected by the Annual Population Survey (APS) relates to the general population and the latest data from this survey.

Smoking Prevalence – West Sussex

Year	% of people 18+ years who stated they were current smokers	Estimated number of current smokers (18+ years) <i>Rounded to nearest 100</i>
2013	16.9	111,000
2014	16.8	111,100
2015	14.6	97,800
2016	15.4	104,200
2017	12.8	87,000
2018	12.5	85,900
2019	10.0	69,000

Data collected by the GP Patient Survey (GPPS) has the prevalence for West Sussex at 12% of adults who describe themselves as either occasional or regular smokers.

Definitions of Sight Impairment – Severity and Main Eye Conditions

A range of terms can be used to describe sight loss, and these may differ according to how sight loss is measured and may also reflect how sight loss impacts the life of the individual.

Severity

Visual acuity (VA) of less than 6/18 (moderate or severe) is largely used as the point which approximates to the statutory threshold for qualifying as registered severely sight impaired (blind) or registered sight impaired (partially sighted).

The definition below is used by the World Health Organisation (WHO) for both adults and children and young people.

Degree of visual impairment	
Blindness	Visual acuity of less than 3/60, or a corresponding visual field loss to less than 10° in the better eye with the available correction.
Severe visual impairment	Visual acuity of between less than 6/60 and 3/60
Moderate visual impairment	Visual acuity of less than 6/18 to 6/60.

WHO¹⁰ classifies vision impairment into two groups: distance and near presenting vision impairment.

Distance vision impairment:

- Mild –visual acuity worse than 6/12 to 6/18
- Moderate –visual acuity worse than 6/18 to 6/60
- Severe –visual acuity worse than 6/60 to 3/60
- Blindness –visual acuity worse than 3/60

Near vision impairment:

- Near visual acuity worse than N6 or M.08 at 40cm.

¹⁰ <https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment>

RNIB state that to have a certificate of visual impairment (CVI) the following definitions are used for severely impaired (blind) and partially sighted (whilst wearing glasses or contact lenses).

<p>Severely impaired have a visual acuity falling into the following categories</p>	<ul style="list-style-type: none"> • less than 3 / 60 with a full visual field. • between 3 / 60 and 6 / 60 with a severe reduction of field of vision, such as tunnel vision. • of 6 / 60 or above but with a very reduced field of vision, especially if a lot of sight is missing in the lower part of the field.
<p>Partially sighted have a visual acuity falling into the following categories</p>	<ul style="list-style-type: none"> • of 3 / 60 to 6 / 60 with a full field of vision • of up to 6 / 24 with a moderate reduction of field of vision or with a central part of vision that is cloudy or blurry. • of 6 / 18 or even better if a large part of your field of vision, for example a whole half of your vision, is missing or a lot of your peripheral vision is missing

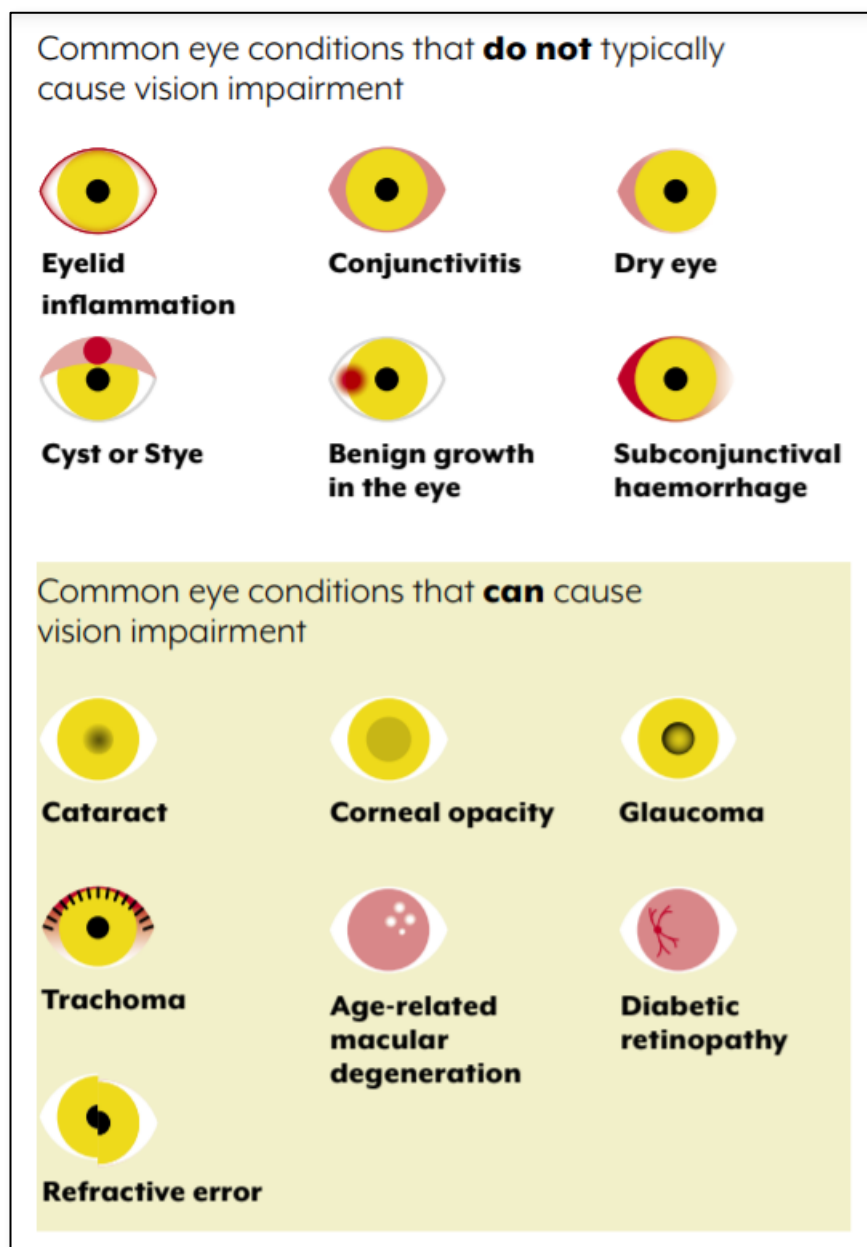
Not everyone eligible for a CVI will have one. RNIB research¹¹ has identified a number of barriers including:

- People being unclear as to the right time to apply for a CVI, notably for people with longer term conditions such as glaucoma. The CVI process is usually initiated by a person's ophthalmologist, but that there is variability in the stage of treatment that ophthalmologists might consider it appropriate to certify patients.
- Lack of awareness of benefits of certification (and subsequent registration with the local authority)
- Lack of encouragement/promotion from professionals, being aware when to ask.

¹¹ RNIB Research Briefing The Certification and Registration Processes: Stages, barriers and delays (2012)

Eye Health Conditions

Not all eye conditions lead to visual impairment. Refractive error is the single largest cause of sight loss, including myopia (short-sightedness) or hypermetropia (long-sightedness). Refractive error can generally be corrected with glasses or contact lenses. The most common conditions needing intervention beyond simple corrective measures are summarised overleaf.



Source: World Health Organisation

Eye Conditions and Risk Factors

Age-related macular degeneration (AMD)	<p>As named, related to ageing. Divided into “wet” and “dry”. Wet AMD affects central vision in a short period of time; if identified early, can respond to treatment although sight loss cannot be restored. Dry AMD progresses slowly, but there is currently no treatment.</p> <p>Factors increasing the risk of AMD:</p> <ul style="list-style-type: none"> • Age – AMD is strongly associated with age • Smoking – Smokers are estimated to be four times more likely to develop AMD than non-smokers¹² • People who have a family history
Glaucoma	<p>Refers to a group of conditions where optic nerve is damaged due to changes in pressure. Early identification is vital so loss can be minimised. Raised intra-ocular pressure (as in Chronic Open Angle Glaucoma (COAG)) is a common form of the condition.</p> <p>Factors increasing the risk of glaucoma¹³</p> <ul style="list-style-type: none"> • Age • Ethnicity – COAG is approximately three times more prevalent amongst black people than white people but the age-related risk increases more rapidly amongst white populations. • Family history • Social and behavioural factors – people from deprived backgrounds are found to present with the condition later and there is emerging evidence of a vascular factor, which means factors such as smoking and obesity could raise the risks (Hogg 2012).

¹² Tan JSL, Mitchell P, Kifley A, Flood V, Smith W, Wang JJ. Smoking and the Long-term Incidence of Age-Related Macular Degeneration: The Blue Mountains Eye Study. Arch Ophthalmol. 2007;125(8):1089–1095.

¹³ NICE <https://cks.nice.org.uk/topics/glaucoma/background-information/risk-factors/>

Diabetic retinopathy	<p>Diabetes can act to affect blood vessels in the eye – which can lead to blindness.</p> <p>Factors that increase the risk for diabetic retinopathy:</p> <ul style="list-style-type: none"> • Risk increases with age • Higher blood pressure • Women with diabetes who become pregnant — or women who develop gestational diabetes — are at high risk for getting diabetic retinopathy.
Cataracts	<p>Related to ageing. The lens of the eye becomes cloudy and can reduce sight. Treatment is by lens replacement.</p> <p>Factors that increase the risk for cataracts include:</p> <ul style="list-style-type: none"> • Age • Smoking • Family history • Alcohol
Uncorrected refractive error	<p>Disorder of focusing light onto the retina - myopia (short-sightedness), hyperopia (long-sightedness; also called hypermetropia), presbyopia (loss of near vision with age) and astigmatism. Can normally be corrected with glasses or contact lenses.</p>
Amblyopia, often called a 'lazy eye'	<p>Developmental disorder where brain does not correctly process the image received from one (or rarely, both) eyes. Develops from birth up to age of approx. seven. Largely preventable if detected at an early age; if not detected in early childhood, generally irreversible.</p>

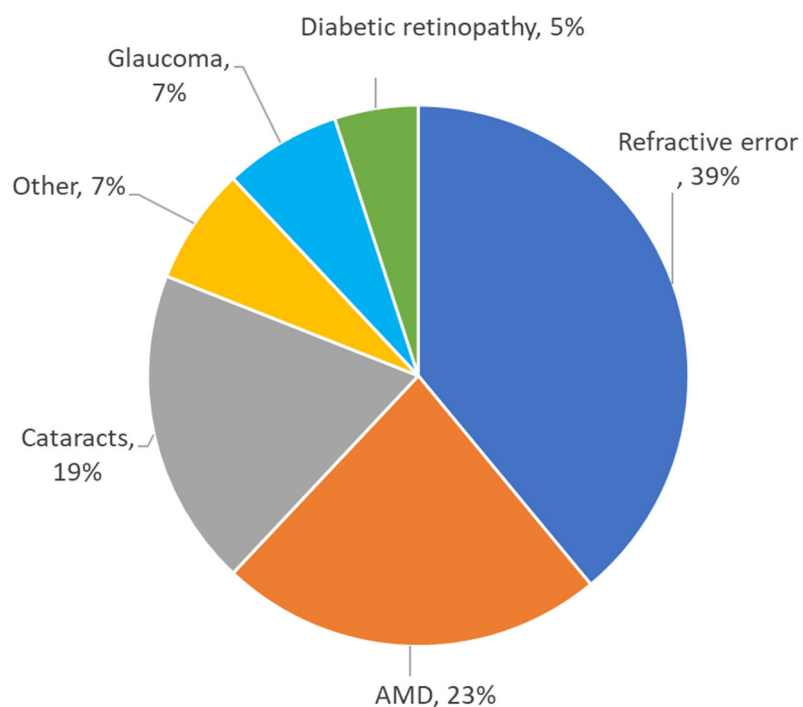
Relative Impact of Conditions on Sight loss

Nationally, RNIB have estimated that at least 2 million people have a sight loss that is severe enough to have a considerable impact on their daily lives.

Over a third of sight loss is attributed to refractive error, approximately a quarter to age-related macular degeneration and then approximately a fifth to cataracts.

Cause of Sight Loss

Source: RNIB The State of the Nation Eye Health 2016



Clinical Definitions – Changes with ICD 11

The codes of the International Classification of Diseases (ICD) are used in certain datasets that contain clinical information – for example, Hospital Episode Statistics – and are useful in linking data from different service sectors, and in identifying the potential impact of visual impairment on service use. In the latest classification of disease (called ICD 11), Group 9 covers ‘Diseases of the Eye and Adnexa,’ which are “any diseases of the visual system, which includes the eyes and adnexa, the visual pathways and brain areas, which initiate and control visual perception and visually guided behaviour.”

<https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment>

Good Eye Health

There are good materials and resources available to promote an awareness of eye health, dispel myths, and encourage individuals and families to be vigilant about their own and their families' eye health.

<https://lookafteryoureyes.org/eye-care/>

Key messages include:

- The importance of regular eye examinations (for most people every 2 years but more frequently if advised by a professional)
- Address modifiable risk factors
 - Stop smoking – smoking being a high-risk factor for a number of eye conditions
 - Exercise
 - Diet – in part to tackle high blood pressure and cholesterol, eating a diet rich in leafy greens and coloured fruit and vegetables, and to maintain a healthy weight.
- Take precaution in higher risk activities including wearing protective eye gear or avoiding chemical or irritants.
- In relation to screen use, adopt the 20/20/20 rule – taking a 20 second break every 20 minutes and focus on something 20 metres away.
- Use of sunglasses to protect eyes from the sun
- Specific advice to maintain eye health in winter, including driving in low-lying sun and adopting strategies to reduce impact of central heating if affected by dry eye.
- Advice on spotting early symptoms of problems in young children and understanding the possible impact of the menopause on eye health.

Policy/National Context

The health and care system is undergoing considerable change. Some developments have been partly impeded by COVID-19, whilst other change, such as the use of digital communications, has been hastened.

In relation to ophthalmology services there are a number of strategic plans, reviews, policies and programmes. Key reports have been set out in chronological order, although it is recognised that work is often reviewed and refreshed.

Some of the reports are more focussed on clinical guidance, which is out of the scope of this report, but it is important to understand the context in which change is taking place.

UK Vision Strategy. An initial strategy was launched in 2008 (this was refreshed in 2013) and set out 3 clear objectives:

1. Improving eye health
2. Eliminating avoidable sight loss and delivering excellent support for people with sight loss
3. Inclusion, participation and independence for people with sight loss

Seeing It My Way Outcomes were developed as part of the UK Vision Strategy, through consultation with over 1,000 blind and partially sighted people. These are clear outcome statements and should be central to any service pathway, planning and delivery.

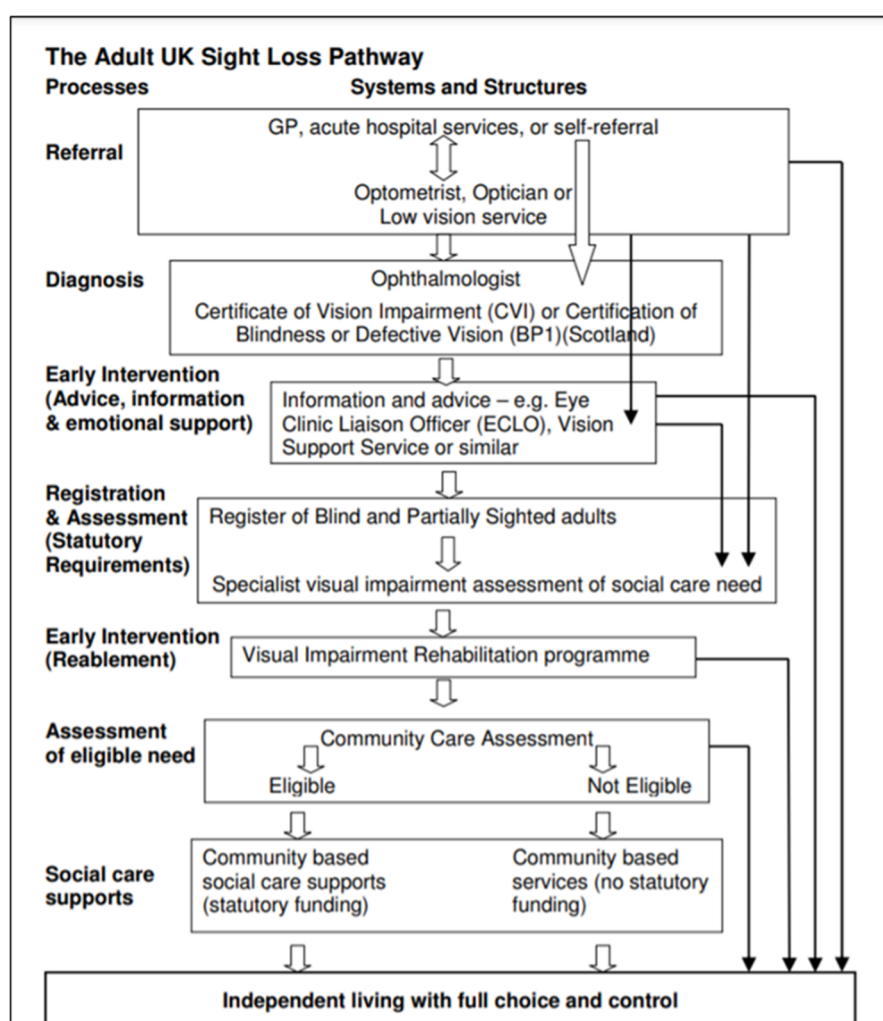
Seeing It My Way Outcomes

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

Adult Sight Loss Pathway

The purpose of this pathway is to set out the various services and professionals supporting someone from referral onwards. This incorporates the range of providers, from high street opticians and specialist acute services, to services providing advice and guidance, and social care support.

As with any pathway, the process is set out linearly, but people may need or benefit from input at different times. Given the range of organisations involved, communication of the pathway to people with a sensory impairment and communication between organisations (so needs do not fall between gaps) is paramount, and this should be clearly articulated by people who commission and deliver services. This is true of all specialities and services. In relation to sight loss, early intervention may prevent deterioration or mitigate effects.



Source: UK Vision Strategy 2013

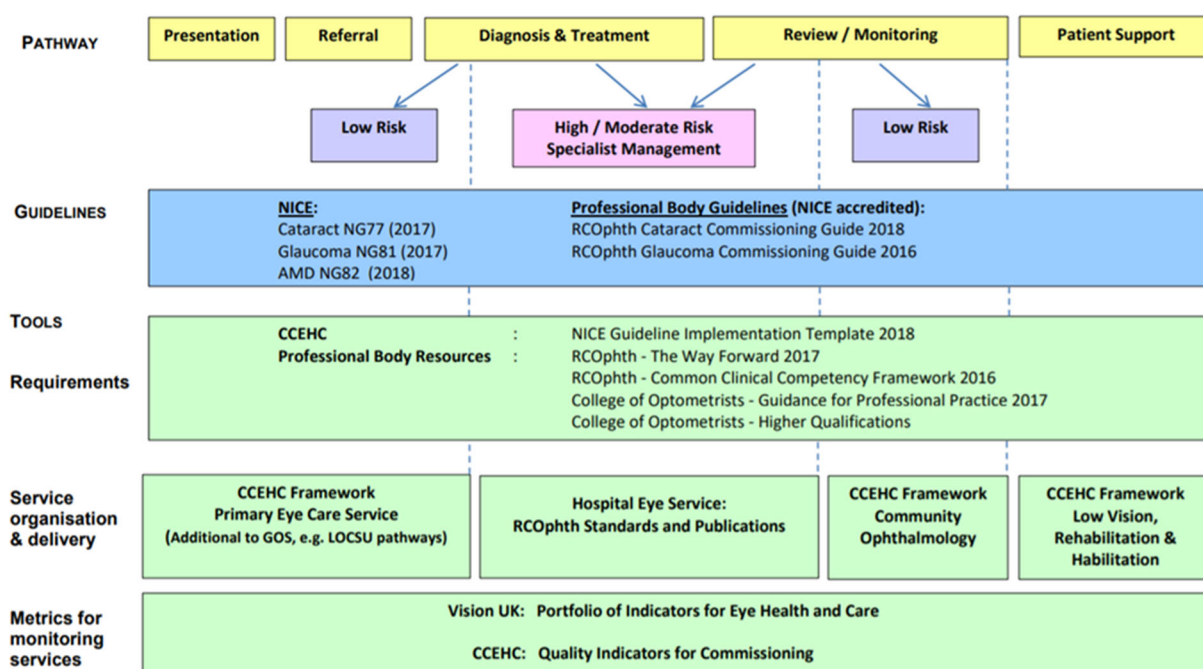
The Way Forward - The Royal College of Ophthalmologists (RCOphth) published The Way Forward in January 2017. This report was based on the interviews of 200 clinical leads across the UK to help identify possible solutions to address rising demand for services, and was centred on cataract, glaucoma, medical retina (encompassing macular degeneration and diabetic eye disease) and emergency eye care. This report also clearly articulated the scale of the challenge. From the interviews, a number of common themes were drawn out:

- **Make better use of existing expertise**, including the need to improve referrals so as to reduce referrals of people with false positive diagnoses and where there may be simple conditions in the community.
- **Maximise use of consultant resource** by building an effective team comprised of both medical and non-medical eye healthcare professionals.
- **Identify optimum patient flow** through hospital clinics, treatment rooms and operating theatres and improve patient experience using: trained multi-disciplinary teams (MDTs); integration of entire patient pathways; improved IT systems; use of virtual clinics and improved communication; and risk stratification to permit Health Care Professionals (HCPs) to see low risk patients to protocol.
- **The importance of discharge policies** and shared care protocols.
- **Enhance working practices within the hospital and the community**, which will be dependent on recruitment and retention, training and skills.

The report notes that changes will require funding and that the importance of well-trained multi-disciplinary teams was frequently noted.

The Clinical Council for Eye Health Commissioning (CCEHC) was established to bring together knowledge from multiple professional bodies to provide collective input to commissioners and providers. CCEHC published a Systems and Assurance Framework for Eye health (SAFE) (below), to support commissioners by encouraging a more strategic and consistent approach to planning.

System and Assurance Framework for Eye-health (SAFE)



Indicators for commissioning and planning

In addition to the summary documents for specific eye conditions and emergency care, CCEHC produced and has reviewed (in 2018) a set of indicators which can be utilised across a service pathway and measures of eye health at a population level.

These indicators have been set out in Appendix 1, with data on broad population measures, adult social care and public health outcomes completed where possible.

The CCEHC eye-specific indicators, identified to monitor the quality, availability and outcomes of eye care and health services, rest with Sussex Commissioners and clinical are set out but data

Other Reports

- **NHS England Elective Care Transformation Programme (ECTP)** ophthalmology was one Wave 2 speciality in this programme which focussed on identifying opportunities to transform services. The key product from this programme (published in early 2019) was an [Ophthalmology handbook](#), using best practice to identify opportunities to improve service delivery.

In this handbook 6 key ideas were explored.

In the area of **referrals**, the following opportunities to improve were identified:

1. **In relation to cataracts – the use of standard referral form** to improve consistency with the aim to see people quickly and improve conversion rates.
2. **Direct referrals from accredited optometrists** directly to secondary care – to reduce GP processing forms
3. **Improved triage of referrals into secondary care**

On **shared decision making**

4. **Patient decision aids** – for example, supporting patients to make informed decisions by the provision of better-quality information about cataract surgery before they are referred into secondary care.

In terms of **outpatients**

5. The use of **virtual clinics** – with clinicians viewing diagnostic information collected by a community setting virtually which may act to reduce referral time and potentially the need for follow up appointments in hospital.
6. **“Failsafe” policies and processes** – to reduce people getting lost or delayed in the system and getting seen by the right practitioner at the right time.

- **Getting it Right First Time (GIRFT) Programme National Specialty Report (2019)**

Getting It Right First Time (GIRFT) is a national programme of clinically-led reviews of services, aiming to improve treatment and care by drawing on evidence, guidance and best practice. In December 2019 the ophthalmology report was published.

WHO World Vision Report (*as recommended for adoption by Member States at the 73rd World Health Assembly in 2020*) has five recommendations:

1. Make eye care an integral part of universal health coverage
2. Implement integrated people-centred eye care in health systems
3. Promote high-quality research
4. Monitor trends and evaluate progress
5. Raise awareness and engage and empower people and communities

In addition to eye specific plans and policies:

- **The Care Act 2014** includes the requirement that local authorities maintain a register of people who are sight impaired, stating that ‘A local authority must establish and maintain a register of sight-impaired and severely sight-impaired adults who are ordinarily resident in its area’. (www.legislation.gov.uk/ukpga/2014/23/section/77).
- **The NHS Long Term Plan.** A key theme of the LTP is the development of Integrated Care Systems bringing together services in a local area to improve the joining up of both the planning and delivery of services to improve population health. West Sussex is part of the Sussex Health and Care Partnership – which has a footprint across West and East Sussex and Brighton and Hove.
- **Equality Act 2010** - Under the Equality Act 2010 a person is defined as being disabled if they have a sustained (12 months or more) physical or mental impairment that affects the ability to undertake everyday tasks. For someone who is certified as blind or partially sighted, they automatically meet the definition. This may also be true of people who are not registered. Of note to visual impairment, the Equality Act includes some specific issues: that information should be accessible, for example where requested available in large print or Braille; and that service providers should make reasonable adjustments for assistance dogs and their owners.

West Sussex Overall Prevalence

To understand how many people in the population are affected by sight loss and specific conditions a range of data sources are needed.

Recorded prevalence relates to the number of people who present to services and are diagnosed. Data on recorded prevalence is presented in the next section.

In this section, the **underlying prevalence** in the population is estimated, as we know that many people may not be diagnosed or are diagnosed at a late stage, so it is important to use available information to estimate the underlying or “true” prevalence in the local population.

There are also a number of ways of describing sight loss and eye health, such as looking at severity, the impact on everyday life and functions and/or by specific conditions.

RNIB provide a tool to estimate overall number of people, called the RNIB Sight Loss Data Tool.

<https://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool>

Using this tool:

- RNIB¹⁴ estimate that approximately **34,000 people in West Sussex (aged 18+) are living with sight loss**, and of these approx. 4,700 are living with blindness.
- Many of the 34,000 people will not have a sight loss that is certifiable, but the impairment will have a significant impact on undertaking daily activities.
- As the main risk factor for sight loss is age, over 20,000 people affected are over 65 and this number will grow as the population ages. In relation to children and young people, RNIB estimate that 330 children aged 0 to 16 are partially sighted and a further 150 young people aged 17 to 25 years.

Estimation of Specific Conditions

For specific eye conditions, this report has mirrored the approach taken in the Surrey and Sussex Eye Health Needs Assessment (2015), using the National Eye Health Epidemiological Model (NEHEM).

¹⁴ Estimates taken from the RNIV Sight Loss Tool for Local Authorities

This model was developed by Public Health Action Support Team (PHAST) to provide estimates, down to a local level, of the most common eye conditions.

The model takes prevalence findings from research and applies these findings to local population figures. In the 2015 Surrey and Sussex Eye Health Needs Assessment, the model was applied to the 2011 census population. This has been updated in the report and restricted to the West Sussex population using the 2020 ONS mid-year population estimates¹⁵. As the NEHEM centres on specific age groups caution should be taken in comparing data from the NEHEM with other datasets, including the Public Health Outcomes Framework (PHOF) measures.

Summary of the prevalence from the NEHEM Model

Using updated population figures the model estimates that there are:

- Over 45,000 with early-stage AMD, with over 7,5000 people with late stage (wet) AMD and 3,600 late stage (dry) AMD.
- 10,500 people with glaucoma in the population (with up to 35,000 suspects), and almost 19,000 people with ocular hypertension.
- 11,600 people (low estimate) with cataracts who may benefit from surgery.

Prevalence Assumptions Using the National Eye Health Epidemiological Model (NEHEM)

Rounded to nearest 10, based on ONS MYE

Prevalence of Age-related macular degeneration (AMD) West Sussex

AMD Cases	NV-AMD Cases (Wet)	Geographic Atrophy Cases (Dry)	Drusen Cases*
10,490	7,450	3,600	45,640
2.76%	1.96%	0.95%	12%

*Drusen cases refer to yellow deposits found in the retina in dry AMD leading to breakdown in function and loss of central vision.

¹⁵ Note: The NEHEM model requires a breakdown of ethnicity for the calculation of AMD and glaucoma prevalence. While population figures are updated on an annual basis, the ethnic breakdown of the local population is less robust outside of the decennial census. For this reason, the 2020 West Sussex population has been broken down using the 2011 ethnic proportions.

Glaucoma

Mean Estimated Glaucoma Cases	High Estimated Glaucoma Cases	Low Estimated Glaucoma Cases	Suspects Under 60	Suspects 60+	Total Suspects	Ocular Hypertension
10,740	15,260	6,730	16,910	17,870	34,780	18,990
1.81%	2.57%	1.13%	5%	7%	5.86%	3.2%

Cataracts

The estimate provided relates to the prevalence of surgical cataracts, meaning those that may affect vision to such a level that they warrant surgery

High Estimate	Low Estimate
39,270	11,610
7.97%	2.36%

Low Vision

Impaired Vision	Low Vision	Severe Sight Impairment
17,450	14,790	2,660
4.59%	3.89%	0.70%

Projected Need

The following outline projected need for working age adults and for people aged 65+ years. The tables are sourced from the tools developed by the NHS and the Institute of Public Care (IPC) and take current prevalence estimates and apply to ONS population projections.

<https://www.poppi.org.uk/>

<https://www.pansi.org.uk/>

Projected Need - People Aged 18 to 64 years

Predicted to have a serious visual impairment	2020	2025	2030	2035	2040
18-24 years	35	35	40	40	35
25-34 years	60	60	55	60	65
35-44 years	70	70	70	70	70
45-54 years	80	75	75	80	80
55-64 years	75	85	85	80	80
18-64 years total	320	325	325	325	325

Projected Need - Older People

Predicted to have a moderate or severe visual impairment (rounded to nearest 100)	2020	2025	2030	2035	2040
Aged 65-74 predicted to have a moderate or severe visual impairment	5,800	5,840	6,710	7,360	7,320
Aged 75 and over predicted to have a moderate or severe visual impairment	12,240	14,480	15,770	17,340	19,580
Aged 75 and over predicted to have registrable eye conditions	6,320	7,480	8,140	8,950	10,110

In terms of scale of demand and projected demand, it is important to note that, as the four main conditions (age-macular degeneration (AMD), glaucoma, cataracts and diabetic eye disease) are age-related, the levels of referral and diagnoses of eye conditions, and people requiring services, will increase as the West Sussex population grows and proportion of older people increases.

Projected Need – Specific Conditions

Condition	2021	2025	2030
Early-stage AMD	46,100	50,500	56,000
Late-stage dry AMD	3,690	4,130	4,760
Late-stage wet AMD	7,560	8,510	9,930
Total late state AMD	10,700	12,000	13,900
Cataract	11,800	13,200	15,300
Ocular hypertension	19,400	20,200	21,100
Glaucoma	11,100	12,100	13,600
Diabetes	61,700	64,800	68,900
Diabetic retinopathy	17,600	18,100	18,800
Severe retinopathy	1,620	1,660	1,730

Source: RNIB Sight Loss Tool

So, demand for services at all points of the pathway will increase, and at the same time the supply of services, including the scale of the workforce, will also need to keep pace. An ageing population will increase the demand for eye health services, from community support to specialist services.

It is also important to consider the co-morbidities of an ageing population, notably in relation to conditions such as dementia but also how issues such as reduced mobility can be addressed by the location and design of clinics.

As a response to an increase in demand, an expanded workforce will be required.

Adult Sight Loss Pathway – at a Local Level

A broad description of the pathway, and associated data, is summarised below.

This report is not reviewing clinical services. These are currently (2021) subject to a review by Sussex Health and Care Partnership (SHCP). Given the importance of linking services to meet needs across the pathway, all information summarised as part of the needs assessment is being provided to the SHCP leads to avoid any duplication of effort

Referral and Diagnosis

Sight Tests

In relation to a sight test, the key functions are:

- To check the internal and external health of the eye
- Provide a prescription to correct refractive error, and to provide the patient with a written statement
- Identifying if there is a need for a referral, and setting out the reason for a referral

Most tests take place at high street opticians and are carried out an optometrist registered with the General Optical Council.

Sight tests are free for some people, including children, and young people up to the age of 18 if in full time education; people in receipt of certain welfare benefits; people registered as partially sighted or blind; people who have a diagnosis of diabetes or glaucoma; and for people aged 40+ who have a parent, sibling or child diagnosed with glaucoma, or have themselves been identified at being of risk of glaucoma. Where people are eligible for free eye tests, data had previously been available at a sub-national level, but at present (July 2021) only national data are published due to data quality issues, and even at national level some contextual information (such as take-up by different ages, benefit recipients etc.) are no longer included in the published data.

Data published in June 2020 stated that, in 2019/20, there were 13,355,060 sight tests across England. There were some trends and findings from the national data that may support planning at a local level:

- There has been a 13% increase in NHS free tests over a ten-year period, with a year-on-year increase over the last 5 years slightly below 1% pa.
- The average number of sight tests per optometrist in 2019/20 was 948.
- 99.9% of tests were undertaken by optometrists
- 3.5% of tests were domiciliary, carried out in a person's home.

In addition to eye conditions leading to severe sight loss and blindness, given that refractive error is the leading cause of moderate visual impairment, it is important that any barriers to accessing sight tests are identified and tackled. However, without data on the number and trend in sight tests and the available workforce, it is difficult to assess the current position.

Hospital Admitted Care

Data from Hospital Episode Statistics from 2017/2018 shows that there has been a rise in West Sussex residents admitted in both elective and non-elective care, with elective increasing from 10,300 in 2017/18 to almost 12,000 in 2019/20 and non-elective increasing from 500 to almost 900. Over 80% of admissions are accounted for by people aged 65 years or over.

Outpatients

New outpatient attendances have remained relatively stable over the same period, with data showing large increases in the follow-up appointments; this increase may warrant further analysis, notably between 2017/18 and 2018/19.

Hospital Activity Data – Admitted Patient Care (West Sussex Residents)

(using Hospital Activity Episode Activity (2014/15 to 2019/20))

Note: As the earliest date within this time series pre-dates ICD 11, ICD 10 codes have been used.

The following codes have been used to summarised activity

Criteria: ICD10 codes - H00-H59, Q10-Q15, C69, T26, S05, E103, E113 E133

Admitted Patients (patients may have had more than one admission)

Age Group	2017/18			2018/19			2019/20		
	Elective	Non-Elective	Total	Elective	Non-Elective	Total	Elective	Non-Elective	Total
Under 16	290	54	344	231	75	306	230	66	296
16 - 19	38	8	46	39	4	43	22	14	36
20 - 24	57	12	69	51	16	67	49	18	67
25 - 29	57	20	77	54	26	80	51	34	85
30 - 34	49	5	54	42	19	61	55	28	83
35 - 39	89	10	99	69	16	85	64	20	84
40 - 44	93	20	113	97	13	110	76	19	95
45 - 49	168	27	195	170	29	199	189	35	224
50 - 54	307	30	337	350	43	393	320	49	369
55 - 59	416	45	461	480	57	537	480	72	552
60 - 64	661	32	693	707	37	744	707	56	763
65+	8,599	235	8,834	9,030	315	9,345	9,694	454	10,148
unknown	8	15	23	5	16	21	24	16	40
Total	10,832	513	11,345	11,325	666	11,991	11,961	881	12,842

Ophthalmology Outpatient Hospital Attendances

(2017/18 to 2019/20)

The following codes have been used to summarised activity

Criteria: Main Specialty - 130 and 460

Attendances (patients may have had more than one attendance)

	2017/18				2018/19				2019/2020			
Age Group	Follow up	New	Others	Total	Follow up	New	Others	Total	Follow up	New	Others	Total
< 16	4,356	1,704	44	6,104	4,455	1,854	37	6,346	3,991	1,724	19	5,734
16 - 19	448	300	5	753	555	311	5	871	631	311	9	951
20 - 24	671	440	3	1,114	789	436	5	1,230	865	411	9	1,285
25 - 29	827	605	5	1,437	1,006	550	6	1,562	1,233	579	9	1,821
30 - 34	940	622	6	1,568	1,196	634	3	1,833	1,272	619	7	1,898
35 - 39	1,249	790	4	2,043	1,476	708	2	2,186	1,664	700	9	2,373
40 - 44	1,621	897	7	2,525	1,884	874	4	2,762	1,966	868	9	2,843
45 - 49	2,484	1,261	6	3,751	3,165	1,191	12	4,368	3,280	1,187	20	4,487
50 - 54	3,583	1,665	12	5,260	4,960	1,578	13	6,551	4,931	1,607	24	6,562
55 - 59	4,465	2,007	14	6,486	6,194	1,909	31	8,134	6,343	1,903	37	8,283
60 - 64	5,816	2,216	19	8,051	7,688	2,288	40	10,016	7,811	2,283	55	10,149
65+	59,682	17,151	345	77,178	76,862	17,568	428	94,858	78,616	17,169	649	96,434
unknown									10	8	3	21
Total	86,142	29,658	470	116,270	110,230	29,901	586	140,717	112,613	29,369	859	142,841

Waiting Times for Treatment – Ophthalmology

Comparable data are published in terms of broad specialities. Information is provided separately in terms of people who were admitted to hospital for treatment and those treated as outpatients. *Given the broad category used, information should be treated with some caution but provides an indication of typical waiting times.*

Prior to 2021, the data are split between the three West Sussex CCGs. This shows some variability between different areas of the county, with lower median wait times for non-admitted care in Crawley compared with Coastal West Sussex and Horsham and Mid Sussex, and higher waiting time for admitted care in March 2020 in Horsham and Mid Sussex.

Admitted Referral to Treatment waiting times (median weeks) for people whose wait ended during the month with an inpatient/day case admission for treatment.

Area	Median Weeks			
	March 2018	March 2019	March 2020	March 2021
England overall	13.5 weeks	13.6 weeks	11.3 weeks	12.0 weeks
NHS Coastal West Sussex	16.7 weeks	14.9 weeks	11.3 weeks	14.5 weeks
NHS Crawley	12.8 weeks	15.8 weeks	14.7 weeks	
NHS Horsham and Mid Sussex	15.1 weeks	19.5 weeks	20.5 weeks	
NHS West Sussex	-	-	-	

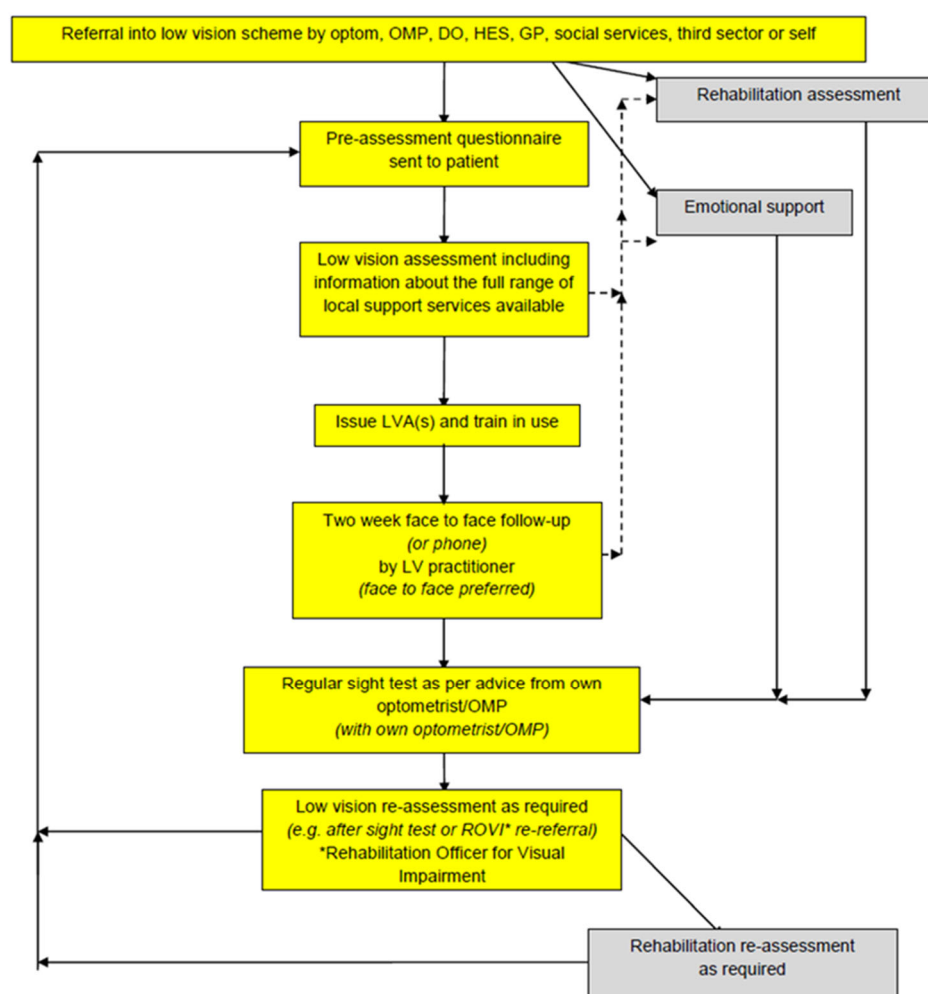
Non-admitted: Referral to Treatment waiting times (median weeks) for patients whose wait ended during the month for reasons other than an inpatient/day case admission for treatment (for example where a person started treatment in an outpatient setting or a non-treatment clock stop).

	Median Weeks			
	March 2018	March 2019	March 2020	March 2021
England overall	6.0 weeks	6.0 weeks	6.1 weeks	6.7 weeks
NHS Coastal West Sussex	11.3 weeks	11.0 weeks	11.8 weeks	17.2 weeks
NHS Crawley	2.4 weeks	2.4 weeks	1.3 weeks	
NHS Horsham and Mid Sussex	10.1 weeks	6.6 weeks	8.3 weeks	
NHS West Sussex	-	-	-	

After Diagnosis

In addition to a statutory requirement to support the registration of blind and partially sighted people and an assessment of social care needs, the Clinical Council for Eye Health Commissioning Framework sets out a pathway so that people have the opportunity for a detailed low vision assessment, which should not be at a single point in time and may need review and re-assessment. This is to support people to make the most of their remaining sight and link them to the services and aids that may help adjustment. Eye Clinic Liaison Officers (ECLOs) often form part of low vision services, although the funding and commissioning approach for an ECLO service is not set out in NHS or NICE guidance. RNIB research (ref) has found that a £1 investment in an ECLO service provides a return of over £10 to health and care services.

Adult Community Optical Low Vision Community Service Pathway



Note given specific interest in the role of Eye Clinic Liaison Officer a rapid literature review was conducted on their role and impact. This is attached (Appendix 2)

Access to Low Vision Services Across West Sussex.

As of October 2021, there remains differences on how people, across West Sussex, have access to low vision services in in West Sussex. The description below pre-dates the merging of CCGs in West Sussex and so describes the position in Crawley, Horsham and Mid Sussex and Coastal West Sussex CCG areas.

Access to Low Vision Services via Crawley and Horsham Hospitals

- In Crawley CCG and Horsham and Mid Sussex CCG, low vision services are delivered via Crawley and Horsham hospitals. *These are funded by Surrey and Sussex Healthcare Trust (SASH).*
- 4Sight deliver the service under a sub-contractor agreement with Sight for Surrey.
- The 4Sight practitioner leading on this clinic is not an optometrist but has completed a 3-week Optima low vision services course.
- There are no eligibility criteria for accessing the SASH low vision clinics.

In Mid Sussex Brighton and Hove CCG stopped funding the Low Vision Services at Princess Royal Hospital in Haywards Heath in 2018. This means patients are required to access a ROVI assessment and self-fund a low vision assessment.

Coastal West Sussex - Coastal West Sussex covers Chichester along with Adur, Arun and Worthing.

Patients attending local hospitals (such as Worthing and St Richards) can obtain a Hospital Eye Services Prescription for by 4Sight Sight Loss Advisors. This covers a low vision assessment and free equipment at participating opticians. This service requires specific vision eligibility criteria to be met.

4Sight provide low vision assessments at a fee across Sussex.

In summary there remains an inconsistency in the access to LVS and eligibility criteria used to access free services. For individuals this means they may not be accessing support and advice, or there may be additional delays in doing so.

Sight Care Advisers

In West Sussex, Sight Care Advisors (SCA) are trained nurses who support people after diagnosis. SCAs refer people to WSCC Adult Social Care, provide information after a diagnosis to support people to understand their condition and the next steps, pathways and services, and act as a gateway to other organisations and support.

The service has a strong preventative ethos, working to prevent escalating needs, such as in relation to frailty, falls, and mental health, and to support people to remain safe, well and independent within their community.

The service is based in the eye clinics at Southlands and St Richard's hospitals and is provided by a charitable organisation 4Sight.

Referrals to 4Sight SCAs 2014/15 to 2020/21

4Sight Vision Support SCA Interaction	2014-15	2015-16	2016-17	2017-18	2018-19	2019-20	2020-21*
Direct referrals from clinic for registration	283	268	280	275	360	283	231
Direct referrals from clinic for advice & support	69	58	75	105	147	188	142
Total Direct Referrals	352	326	355	380	507	471	373
All other contacts (telephone and email)	1,320	1,320	1,320	919	1,257	2,382	1,812
Low Vision Assessments	264	218	255	200	228	253	259

Source: 4Sight Activity Data

The hospital eye clinics have been referring between 270 and 360 people directly to the SCAs for CVI. The NICE Quality Standard for Serious eye disorders reinforce the importance of timely certification and recommend that service providers have systems in place to provide information on the support, services and benefits accompanying certification (NICE QS, 2019).

Registration is a key point on the pathway, an important gateway for patients to access financial, practical, emotional and social support services.

The literature review (Appendix 2) highlights the importance of good (well-completed) and timely certification and subsequent registration.

West Sussex SCAs work with the patient to complete the CVI, which is signed by the ophthalmologist, and this creates an onward referral to social care and other agencies.

4Sight have estimated that the CVI certification process takes, on average, an hour and a quarter to complete but clearly, given the impact of a sight loss diagnosis, this should not be viewed as an administrative task.

In addition to CVI registration, eye clinics can refer patients to SCAs for support and advice. The service undertakes approximately 250 low vision assessments a year and answers email and phone queries from patients, carers and other professionals.

****Note: Sight Care Advisors - Impact of COVID – Services from April 2020***

Due to the impact of COVID-19, adaptations were made to the services with the face-to-face Sight Care Advisor Service moving to a remote service from April 2020 in order to support Ophthalmology teams in Southlands and St Richard's hospital Eye Clinics

Preventable Sight Loss - Sight Loss Certifications

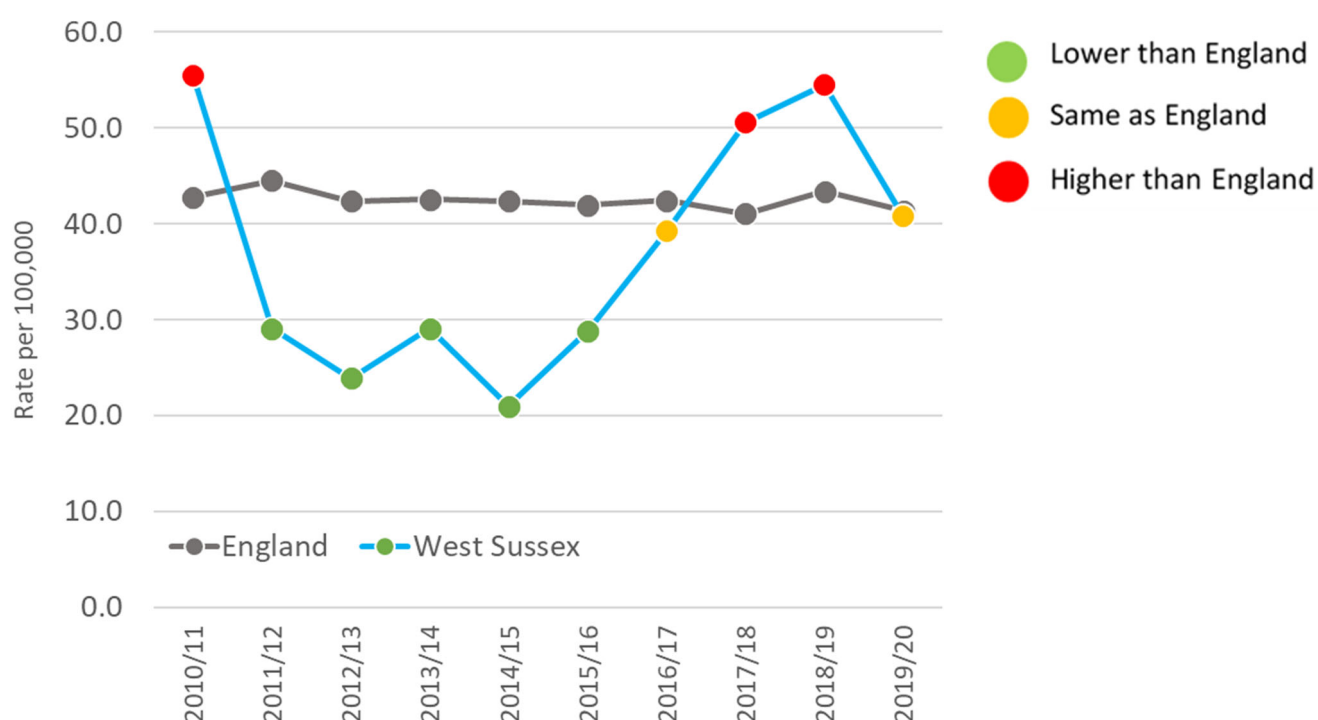
Data relates to a completion of a CVI (certificate of visual impairment) by a consultant ophthalmologist and includes new certifications for all causes, both those considered preventable and non-preventable.

Note that In 2019/20, there were **352 new CVI certifications in West Sussex**, a rate of 40.2 per 100,000 population (aged 12+). This was similar to the England rate of 41.4 per 100,000.

- Since 2014/15, the general trend in West Sussex has been an increasing rate of new certifications.

Sight loss certifications per 100,000 population (all ages)

West Sussex and England 2010/11 to 2019/20



Data source: Public Health England

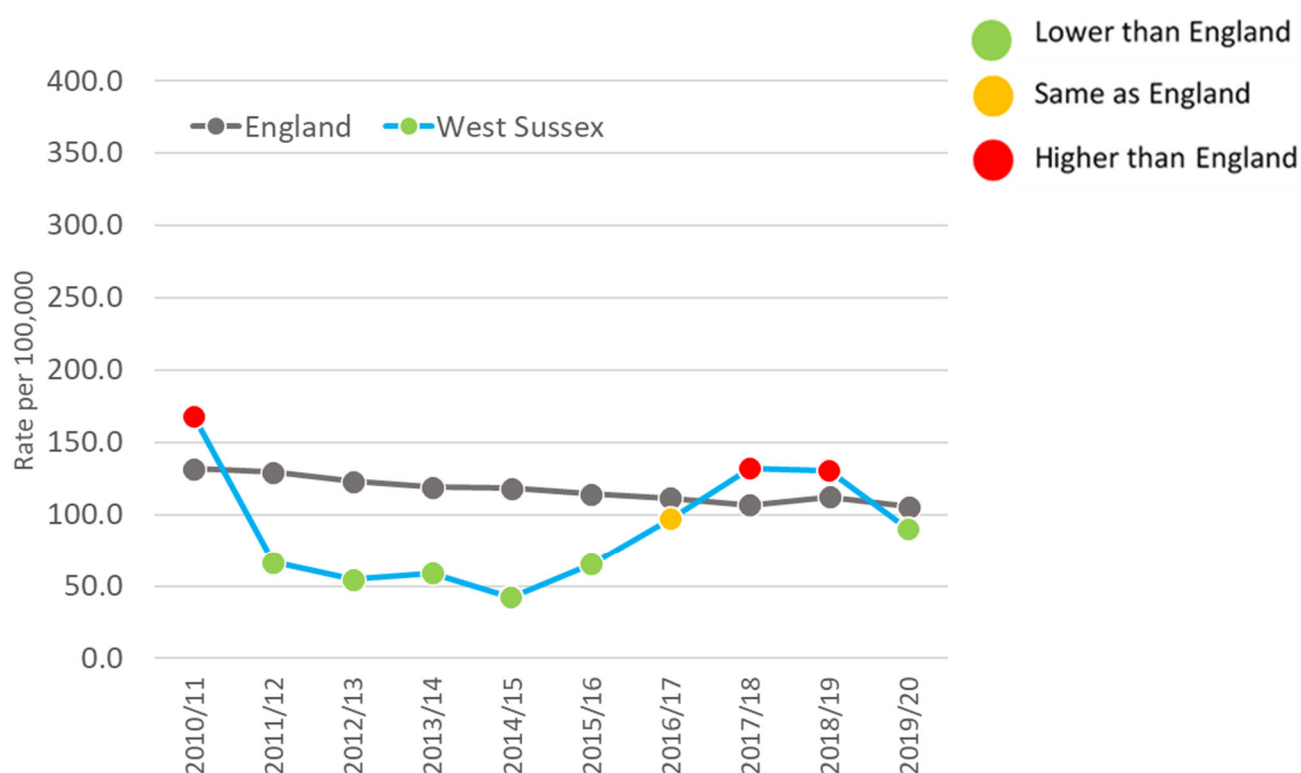
CVI - Age Related Macular Degeneration (AMD)

This indicator relates to people aged 65+ years or over with sight loss due to AMD as the main cause, or in the absence of a main cause, with AMD is listed as a contributory cause. Age-related macular degeneration (AMD) is the leading cause of certifiable sight loss in the UK.

PHE data estimate that **178 people in West Sussex in 2019/20** were recorded as having sight loss due to age-related macular degeneration. This was a rate of 89.5 per 100,000 people aged 65+ years. Although this rate is below the England rate (105.4 per 100,000), the rate in West Sussex has been increasing since 2014/15 (where fewer than 100 people had AMD-related sight loss), with over 250 people affected in 2017/18 and 2018/19.

Preventable sight loss - Age Related Macular Degeneration (AMD) (65+ years)

West Sussex and England 2010/11 to 2019/20



Data source: Public Health England

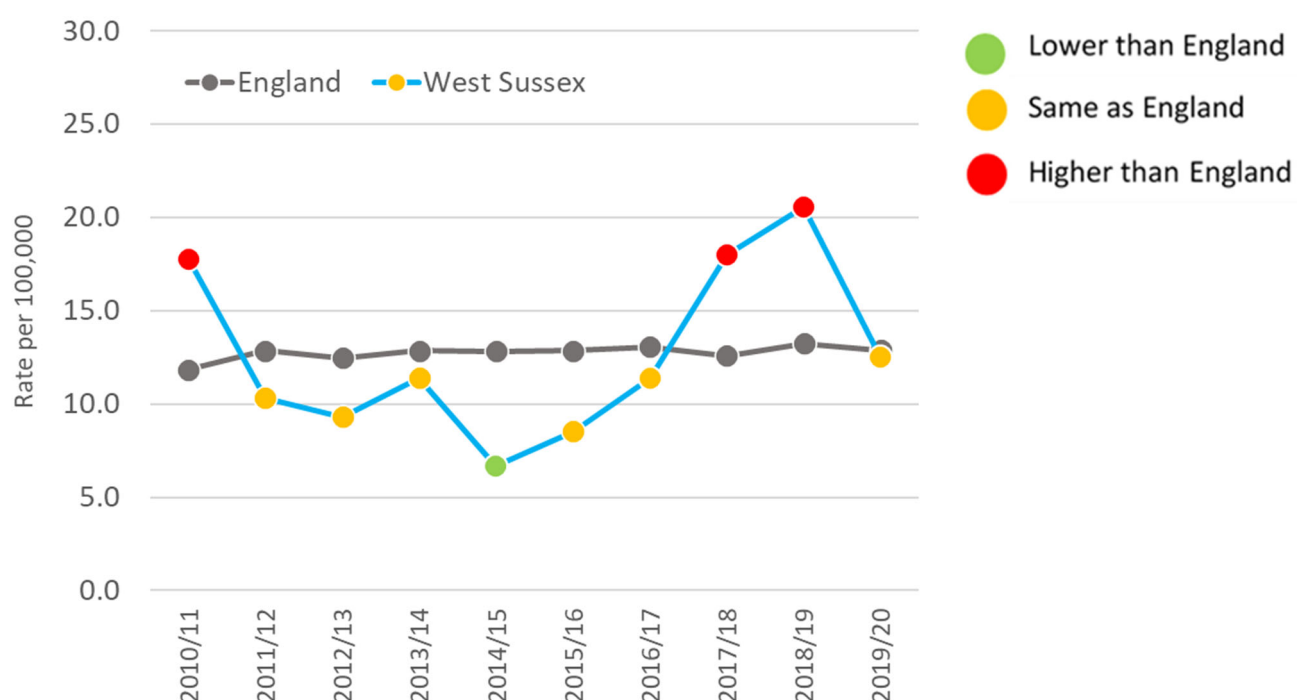
CVI - Glaucoma

This indicator relates to certifications with a main cause of sight loss due to glaucoma, or where no main cause is attributed but where glaucoma is a contributory cause.

In 2019/20, **61 people in West Sussex were recorded as having sight loss due to glaucoma**, representing a rate of 12.5 per 100,000, similar to the England rate. Since 2014/15, there has been an increasing trend in relation to glaucoma.

Preventable sight loss - glaucoma (Persons, 40+ yrs)

West Sussex and England 2010/11 to 2019/20



Data source: Public Health England

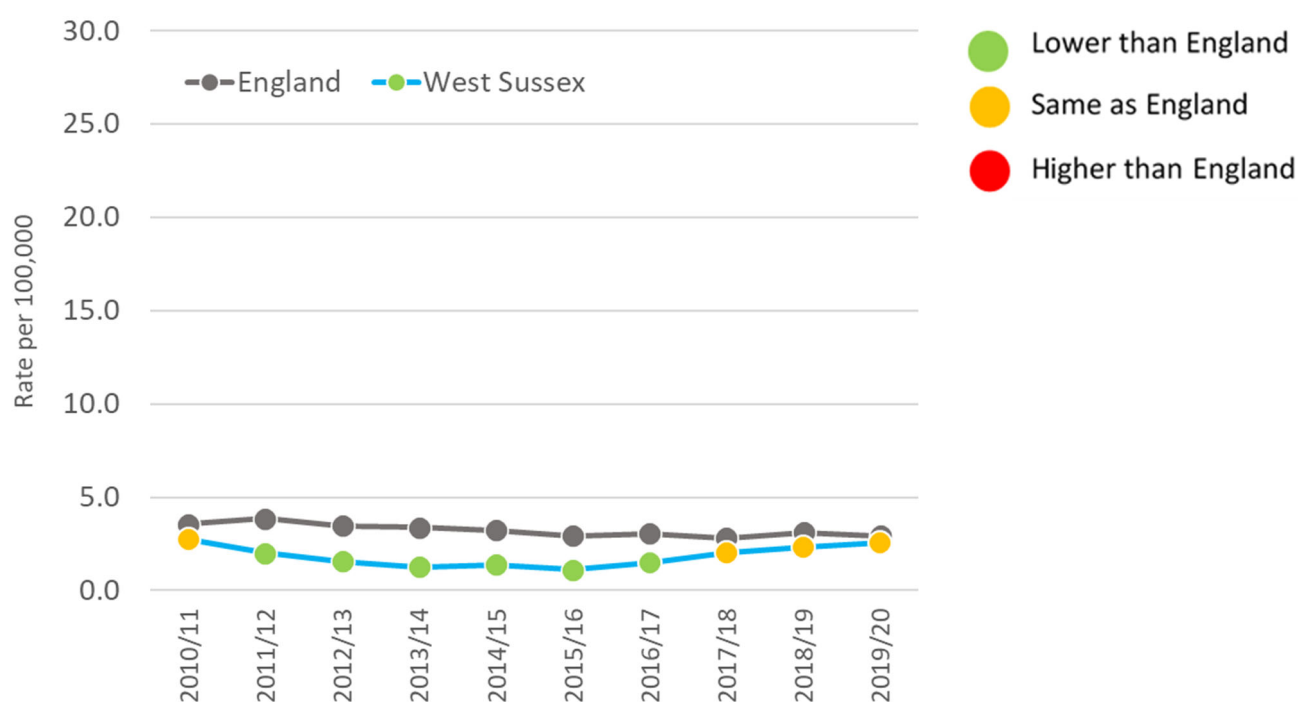
CVI - Diabetic Eye Disease

This indicator looks at sight loss due to diabetic eye disease, where it is noted as the main cause or if no main cause as a contributory cause. This does not include diabetics who have a visual impairment due to *any* cause.

In 2019/20, **19 people in West Sussex were recorded as having sight loss due to diabetic eye disease**, representing a rate of 2.6 per 100,000, similar to the England rate.

Preventable sight loss - diabetic eye disease (Persons 12+ years)

West Sussex and England 2010/11 to 2019



Data source: Public Health England

Registration and Assessment (Statutory Assessment) / Early Intervention (Rehabilitation)

Specialist rehabilitation officers for the visually impaired (referred to as ROVIs) are part of the Sussex County Council's Adult Sensory Services Team. This team provides support to adults who are blind, Deaf, hearing impaired or have dual-sensory (sight and hearing) loss.

The team support people by providing advice and information, undertaking assessments at a person's home, helping to advise and direct people to the support available, and supporting in a range of practical issues, from accessing welfare benefits and helping people register as sight impaired to providing training in terms of daily living skills and using equipment.

People can self-refer to the team for support.

Certificate of Visual Impairment and Local Authority Registers

Local authorities are required to hold a register of people who are blind or sight impaired. Although encouraged to be included on a register, people that have a Certificate of Vision Impairment (CVI) from an ophthalmologist may choose not to be registered. Not being on a local authority register should not affect the access to assessment or services. However, for the individual, being on the local authority register may help access some benefits and services, or ease access to them; and data collected as part of registration can support service planning and delivery, providing an understanding of scale and trend.

Upon receipt of a CVI, West Sussex County Council staff will contact the person and arrange a care and support needs assessment, if required, and provide advice about aids, services and adaptations.

Councils are not required to maintain registers in relation to hearing loss or physical disabilities.

Data are collected on people

- In total (in 2019/20) there were 5,995 people registered as sight impaired. Of these, 3,790 were registered blind/severely sight impaired and 2,205 were registered as partial sight/sight impaired.

Total Number of People on Register 2019/20 (rounded to nearest 5)

Age Group	Blind/severely sight impaired persons	Partial sight/sight impaired persons
0-4	data suppressed (<5)	data suppressed (<5)
5-17	data suppressed (<5)	data suppressed (<5)
18-49	245	135
50-64	280	140
65-74	250	170
75 and over	3,015	1,760
Total	3,790	2,205

Source: SSDA902 Collection 2019-20, NHS Digital

- Of those people on the register who are blind/severely sight impaired (these figures are rounded to the nearest 5 by NHS Digital):
 - 25 are also recorded as being deaf and without speech,
 - 10 recorded as deaf with speech, and
 - 45 hard of hearing.

People NEW to the Register 2019/20 (rounded to nearest 5)

- 415 people were new to the register in 2019/20.

Age Group	Blind/severely sight impaired persons	Partial sight/sight impaired persons
0-4	data suppressed (<5)	data suppressed (<5)
5-17	data suppressed (<5)	data suppressed (<5)
18-49	20	15
50-64	15	15
65-74	20	15
75 and over	190	125
Total	245	170

Source: SSDA902 Collection 2019-20, NHS Digital

Data are also recorded on any other disabilities that people who are on the register may have.

Other Disabilities of People on the Register 2019/20

Disability	Blind/severely sight impaired persons	Partial sight/sight impaired persons
People who are deaf with speech	25	data suppressed (<5)
People who are deaf without speech	10	10
People who are hard of hearing	45	10
People with physical disabilities	data suppressed (<5)	data suppressed (<5)
People with mental health problems	data suppressed (<5)	data suppressed (<5)
People with learning disabilities	10	data suppressed (<5)
Total	95	25

Source: SSDA902 Collection 2019-20, NHS Digital

Social Care – Long-Term Support



Note the data below only relates to people whose **primary care** need has been recorded as a sensory impairment. There will be many people who have a sensory impairment but have a different primary support reason recorded. The data have been included to enable comparison with England and change over time. At county level numbers are low, but using data grouped at CIPFA comparator authority level it is apparent that there is a decline in the provision of long-term support with sensory impairment (whether visual, sight or both). This should not be assumed to reflect need, it may reflect access to services.

A snapshot of people in receipt of social care support in November 2019, found, irrespective of their primary support reason, approximately 180 people were blind, and a further 250 had a visual impairment recorded.

During the year 2020/21, 25 adults aged under 65 years and 125 adults aged 65 years or over were receiving long term social care support and had a primary support need given as visual impairment; 10 people under 65 years and 30 people over 65 years had a primary support need stated as hearing impairment; and 5 people under 65 years and 35 people over 65 years had dual impairment.

Number of West Sussex residents accessing long term support during 2020/21 with a sensory impairment as the Primary Support Reason and Age Band (rounded to nearest 5)

Primary Support Reason	18 to 64 years	65 years or over
Visual Impairment	25	125
Hearing Impairment	10	30
Dual Impairment	5	35

Previous Years (2016/17 to 2019/20)

As the numbers of people supported at county level are relatively small, it can be difficult to identify whether, over time, numbers have changed. As comparable data will not be published until the end of 2021, information from previous years is shown on the tables below. Overall figures (to the nearest 5) and a rate per 100,000 population is provided for West Sussex and the total for a group of comparable local authorities. This group of local authorities comparable to West Sussex – called the CIFPA group – comprises Cambridgeshire, Devon, East Sussex, Essex, Gloucestershire, Hampshire, Kent, Northamptonshire, North Yorkshire, Oxfordshire, Somerset, Staffordshire, Suffolk, Warwickshire and Worcestershire.

In terms of support to people aged 18 to 64 years, the rate per 100,000 has remained relatively stable, although at an aggregated local authority level there has been a fall in the people receiving support whose primary support reason was recorded as hearing impairment.

People in receipt of long-term support during the year per 100,000 adults (2019/2020) People aged 65+ (rounded to nearest 5)								
PRIMARY support reason VISUAL IMPAIRMENT								
	2016/17		2017/18		2018/2019		2019/20	
	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000
West Sussex	180	95	165	85	155	80	145	75
CIPFA Group	1,285	45	1,205	45	980	35	935	30
PRIMARY support reason HEARING IMPAIRMENT								
	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000
West Sussex	30	15	30	15	25	15	25	10
CIPFA Group	525	20	485	15	400	15	385	15
PRIMARY support reason DUAL IMPAIRMENT								
	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000
West Sussex	35	20	35	20	35	20	35	20
CIPFA Group	485	15	385	15	330	10	320	10

People in receipt of long-term support during the year per 100,000 adults (2019/2020) People aged 18-64 (rounded to nearest 5)								
PRIMARY support reason VISUAL IMPAIRMENT								
	2016/17		2017/18		2018/2019		2019/20	
	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000
West Sussex	15	5	20	5	20	5	20	5
CIPFA Group	480	5	450	5	380	5	370	5
PRIMARY support reason HEARING IMPAIRMENT								
	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000
West Sussex	10	0	5	0	5	0	10	0
CIPFA Group	275	5	235	5	180	0	185	0
PRIMARY support reason DUAL IMPAIRMENT								
	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000
West Sussex	5	0	5	0	5	0	5	0
CIPFA Group	185	0	190	0	160	0	155	0

APPENDIX 1 - Indicators

Broad Population Indicators – Eye Health (CCEHC, 2018) From the Public Health Outcomes Framework

Indicator	Link to Eye Health	Latest Data Available
Social Isolation - % of adult social care users who have as much social contact as they would like	Sight impairment / sight loss can be a contributory comorbidity	2019/2020 West Sussex 48%, SE 45.5%, England 45.9%
Percentage of adults classified as overweight or obese	Modifiable risk factors for systemic disease associated with sight impairment / loss	2019/2020 West Sussex 61.7%, SE 61.5%, England 62.8%
Proportion physically active and inactive adults	Modifiable risk factors for systemic disease associated with sight impairment / loss	2019/2020 – Active 18+ West Sussex 68.4%, SE 69.5%, England 66.4% 2019/2020 – Inactive 18+ West Sussex 20.9%, SE 20.1%, England 22.9%
Prevalence of smoking among persons aged 18 years and over	Modifiable risk factors for systemic disease associated with sight impairment / loss	2019/2020 (APS Survey Data) West Sussex 10%, SE 12.2%, England 13.9%
Recorded diabetes	Systemic disease associated with sight impairment / loss	2018/2019 CCG Level Data from QOF Registers Coastal West Sussex 7.6% of 17+ population (32,724 patients) Crawley – 7.5% of the 17+ population (7,886 patients) Horsham and Mid Sussex – 5.6% of the 17+ population (10,989 patients)
Injuries due to Falls	Sight impairment / sight loss can be a contributory comorbidity	Emergency hospital admissions due to falls in people aged 65 and over – 2019/20 – 5,440 admissions rate of 2,521 per 100,000. SE 2,326 per 100,000, England 2,222 per 100,000
CVI – preventable sight loss	AMD, Glaucoma, Diabetic Eye Disease, and All-cause certification	Data as per PHOF outcomes framework: AMD - 178 people in West Sussex in 2019/20 rate of 89.5 per 100,000; Glaucoma 61 people in 2019/20 a rate of 12.5 per 100,000; Diabetic Eye Disease - 19 people in 2019/20 a rate of 2.6 per 100,000.

From the **NHS Outcomes Framework**

Indicator	Link to Eye Health	Latest Data available
Health related quality of life for people with long term conditions	Sight impairment / sight loss can be a contributory comorbidity	Jan to March 2017 (GP Patient Survey) Directly standardised adjusted health status (EQ-5D™) score for patients 18+ who state that they have a LTC Coastal West Sussex CCG – 0.751 Crawley CCG – 0.757 Horsham and Mid Sussex CCG – 0.779 England 0.737
Proportion of people feeling supported to manage their condition	Sight impairment / sight loss can be a contributory comorbidity	January 2019 to March 2019 – West Sussex 60.7% (England 58.4%)
Employment of people with long term conditions	Sight impairment / sight loss can be a contributory comorbidity	Oct 2019 to Dec 2019 – Indicator - <i>difference</i> in employment rate between the England population and people with a long-term condition. West Sussex 10.8%, England 10.6%
Outpatient experience	Service provision	Refer to Sussex Commissioners Not clear on outpatient survey data source
In-patient personal needs	Service provision	Refer to Sussex Commissioners https://nhssurveys.org/
Improve access to primary care (GP)	Service provision	Refer to Sussex Commissioners https://gp-patient.co.uk/

From the **Adult Social Care Outcomes** Framework

Indicator	Link to Eye Health	Latest Data available
Proportion of people using social care who receive self-directed support, and those receiving direct payments	Care provision	<u>2019/2020</u> Proportion of people receiving self-directed support - West Sussex 29.4%*, SE 88.4%, England 91.9% *has only included direct payments Those receiving direct payments - West Sussex 29.4%, SE 27.9%, England 27.9%
Proportion of people who use services, and their carers reporting they have as much social contact as they would like	Sight impairment / sight loss can be a contributory comorbidity	<u>2019/2020</u> Service users - West Sussex 48.0% SE 45.5%, England 45.9% Carers – n/a
Satisfaction of people using services with care and support	Care Provision. Sight loss pathways (Adults, Children and Young People) could apply	<u>2019/2020 (Composite score)</u> West Sussex 66.1 SE 64.6 England 64.2
Satisfaction of carer with social services	Care Provision. Sight loss pathways (Adults, Children and Young People) could apply	<u>2018/2019</u> (Survey of carers every 2 years) West Sussex 41.7 SE 38.2 England 38.6
% of people who use services who find it easy to find information about support	Care Provision. Sight loss pathways (Adults, Children and Young People) could apply	<u>2019/2020</u> Service users - West Sussex 71.6% SE 69.3% England 68.4% <u>2018/2019</u> (Survey of carers every 2 years) Carers – West Sussex 71.6% SE 62.9% England 62.5%

Eye Specific Indicators

INDICATOR	
Screening	
% of school entry children (4-5yrs) having vision screened	Data from HCP programme
Proportion of those offered diabetic eye screening who attend a digital screening event (all ages) Source: https://www.gov.uk/government/publications/diabetic-eye-screening-2018-to-2019-data	Using the indicator of uptake of routine digital screening event <i>The proportion of those offered routine digital screening (RDS) who attend a routine digital screening event where images are captured</i> Data for 2018/19 <ul style="list-style-type: none"> ○ NHS Coastal West Sussex 87.5% ○ NHS Crawley 79.3% ○ NHS Horsham and Mid Sussex 83.8%
% children and young people aged 12-24 years diagnosed with diabetes that are screened	No data available at a local level – refer to Sussex Commissioners
General Ophthalmic Services	
Uptake of NHS sight tests in age groups: 0-15 years of age and 60 years of age and over	No data available at a local level – refer to Sussex Commissioners
Presentation / Referral	
Number (and %) of CCGs in England (or by defined commissioning body in devolved nations) procuring a <u>Glaucoma</u> Referral Filtering Pathway for (a) repeat measurement service (b) enhanced case finding service	refer to Sussex Commissioners
Number (and %) of participating practices in <u>Glaucoma</u> Referral Filtering Pathways for (a) repeat measurement <i>and / or</i> (b) enhanced case finding; by CCG (in England);	refer to Sussex Commissioners
<u>Cataract</u> Referral Pathway commissioned	refer to Sussex Commissioners
<u>AMD</u> Referral Pathway commissioned	refer to Sussex Commissioners

Diagnosis and Treatment	
Visual Acuity outcomes of <u>Anti-VEGF therapy</u> at baseline and at one year after starting treatment for: (i) wet AMD (ii) Diabetic Macular Oedema (DMO) (iii) Retinal Vein Occlusion -Central (CRVO) and Branch (BRVO).	refer to Sussex Commissioners
Visual Acuity outcomes of <u>Cataract Surgery</u> : (i) Visual acuity at time of surgery (pre-operative); (ii) Visual acuity at 4-6 weeks post-operative assessment	refer to Sussex Commissioners
% of R3A M0 and R3A M1 Diabetic Eye Disease seen within 6 weeks of screening event.	refer to Sussex Commissioners
% prescribing for generic prostaglandin analogue (eye drops) for Glaucoma	refer to Sussex Commissioners
Review and Monitoring	
% Hospital appointments that occur within 25% of their intended follow up period, including rescheduling of hospital-initiated cancellations and non-attendance	refer to Sussex Commissioners
Audit of certification of visual impairment (CVI): (i) where the primary cause of vision impairment in Adults is due to Age Related Macular Degeneration (AMD), Glaucoma and Diabetic Eye Disease (ii) in Children by primary cause	(i) Data as per PHOF outcomes framework: AMD - 178 people in West Sussex in 2019/20 rate of 89.5 per 100,000; Glaucoma 61 people in 2019/20 a rate of 12.5 per 100,000; Diabetic Eye Disease - 19 people in 2019/20 a rate of 2.6 per 100,000 (ii) no local data
Monitoring Pathway commissioned for <u>low risk or stable OHT and suspect COAG</u>	refer to Sussex Commissioners
Monitoring Pathway commissioned for <u>early AMD, late dry AMD, and patients discharged from hospital</u> (secondary care)	refer to Sussex Commissioners
<u>Post-op Cataract Pathway</u> commissioned and provided within the Hospital Eye Service, Community or both.	refer to Sussex Commissioners

Patient Support	
Eye Care Liaison (ECLO) Service commissioned and provided within the Hospital Eye Service, Community or both.	Need a description of how services commissioned
Low Vision, Habilitation, and Rehabilitation Services (LVHRS) commissioned and provided within the Hospital Eye Service, Community or both.	Need a description of how services commissioned
Registered blind and partially sighted persons: number registered and number of new registrations at time of reporting	<p>In total (in 2019/20), there were 5,995 people registered as sight impaired. Of these, 3,790 were registered blind/severely sight impaired and 2,205 were registered as partial sight/sight impaired.</p> <p>There were 352 new registrations in 2019/20.</p>

APPENDIX 2 - Literature Review of Low Vision Services – Eye Clinic Liaison Officers

As part of this needs assessment and given the lack of clarity in terms of current and future commissioning of “low vision “services a rapid review of the literature was undertaken. In response to a request by the West Sussex Joint Strategic Director of Commissioning this review centred, although not solely, on the role and functions of Eye Clinic Liaison Officers.

Summary of Rapid Literature Review

- That the tasks of any service need to be well-defined (they are not always well specified), and it is important that clinical staff understand and help shape their role
- The population served must be clear, some papers note benefits not just to newly diagnosed patients, people should be able to enter a pathway at the right time to receive the right care, this should not be assumed a one
- Costs – it is unlikely, if the tasks are well-defined, costs would be cheaper outside of the not-for profit sector.
- The specialist nature of the role is noted in a number of papers, and the ability of ECLOs to maintain knowledge of local services, whereas other non-specialists may struggle to do so.
- While NICE does not prescribe the ECLO role (including how they should be funded or employed) there is reference to ECLOs within specific guidance from NICE and in DHSC guidance which assumes the presence of the role (or rather the functions) and these have a close alignment to pathways. Of note NICE recommendations (ref) for a quality ophthalmology service refer to many ECLO functions.

In summary

- There is a function (which guidance and pathways expect to be present) it is valued, with tangible and intangible benefits.
- Functions and tasks are often poorly defined and restricted to newly diagnosed. Commissioners need to clearly, and transparently, specify functions, pathways, responsibilities and accountably and how services meet the needs of all potential users.
- It is highly likely that the function would be more expensive to deliver within the statutory sector.

Eye Clinic Liaison Officers (ECLOs) Rapid Evidence Review (January 2021) Catherine Wells & Clare D Toon

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Background and Context

In the UK, there are almost two million people living with sight loss, the diagnosis of which may lead to significant mental and/or emotional issues and wider social impacts. Individuals who are visually impaired may also be at risk of falls, isolation and depression.

In order to minimise the incidence of these issues, many eye clinic patients will be referred to an Eye Clinic Liaison Officer (ECLO), providing support and guiding people through the process of registration of visual impairment, application of relevant benefits, and the availability and use of aids and services to assist and make adjustments.

This paper seeks to understand the role, demand for, and efficacy of ECLOs.

Initially, the role of the ECLO will be explored, including its origins and specification. This is followed by a review of the available evidence, along with a look at both local and national costings. However, it should be noted that several of these papers are not peer reviewed and are relatively old (two or more years). It should further be noted that due to the complex nature of the intervention and outcomes there have been no randomised controlled trials (RCTs) conducted within this field. National guidelines and grey literature are also included.

What are ECLOs and why are they needed?

What are ECLOs?

Eye Care Liaison Officers are recommended by the Royal National Institute for the Blind (RNIB) and may be known by one of several different titles. The Scottish equivalent of the ECLO, for example, is the Vision Support Officer. Other titles include Sight Loss Advisor, Low Vision Co-ordinators, Low Vision Support Workers, Information Officers, and Independent Living Advisors (Gillespie-Gallery, Subramanian, & Conway, 2013).

On a local level (within Western Sussex Hospitals NHS Foundation Trust (WSHT)), they are referred to as Sight Care Advisors (SCAs). For the purpose of this document, the term ECLO will be used throughout.

The local ECLOs are employed by a Sussex-based charity called 4Sight Vision Support. They based within the sight care clinics placed within WSHT and form an integral part of the ophthalmology service.

The staff at WSHT pre-date the RNIB's recommendation, having been in place since 1998 and are trained nurses, setting them apart from some similar ECLO services.

They operate an 'open door' policy, and accept referrals directly from patients, family members, and the ophthalmological services they work within (Support, 2020).

What do ECLOs do?

The core activities of an ECLO are outlined in the RNIB's ECLO Quality Framework and Practice Guidelines (Blind, 2019), and include the following:

- providing emotional support for patients, families, and carers,
- providing practical information, including advice on the process and benefits of certification of visual impairment and subsequent registration,
- undertaking an initial support needs assessment,
- referrals on to statutory services, support groups and voluntary organisations,
- establishing professional networks and mechanisms to support the referral function, and
- the monitoring and follow-up of patient progress.

The evidence, albeit limited, suggests that the majority of ECLOs share the same core responsibilities, as outlined above and in the RNIB Framework. However, there is variability in the provision of both core, and additional, tasks between NHS trusts. This variety may reflect lack of rigor, and small sample sizes within the studies reviewed. These studies included diary reviews from 11 ECLOs over a two-week period (Subramanian, Gallery, & Conway, 2012); a checklist of activities completed by 18 ECLOs (Gillespie-Gallery et al., 2013); a series of 141 interviews with health and social care professionals working with, or with a working knowledge of, ECLOs (Llewellyn, Hilgart, Joshi, & Williams, 2019); and a retrospective

observational study of ECLOs employed by the RNIB across 83 NHS Trusts within UK (Papastefanou, Kang, Simkiss, & Zambarakji, 2020).

All studies identified ECLO provision of practical information and support to patients as the main responsibility. Information commonly included discussion with the patient of their eye condition and treatment, along with an explanation of the registration process. Also noted was information on education, employment, and specialised equipment and aids. However, the provision of training in the use of these aids was only noted in one study (Gillespie-Gallery et al., 2013). Support came mainly in the form of signposting and onward referrals to local support services.

Papastefanou and his colleagues reviewed the records of 4,139 eye clinic patients (Papastefanou et al., 2020). This study noted that the three most common onward referrals were to social services (37.2%), low vision services (22.3%) and local support services (13.6%). Other services, such as equipment/aids groups and welfare and disability entitlements, were referred to far less frequently (5.7% and 5.6%), and others, such as employment support and falls prevention teams, even less so (2.2% and 0.7%). Emotional support and counselling also represented a significant role for the ECLOs, despite counselling seemingly falling outside the RNIB-defined remit of their role (Pybis, Thurston, Dennison, Broom, & Miller, 2016).

The high degree of variation in the roles and duties undertaken by ECLOs from different NHS trusts has been acknowledged by the RNIB in their Framework, which states that:

Historical influences...and the expectations/perspectives of all relevant stakeholders will determine the nature of a sight loss support service
(Blind, 2019)p3)

The effect of clinical staff's perceptions of what an ECLO service should look like and when to use it may negatively influence its effectiveness and impact on patient care. For example, the misperception that ECLOs were only for the newly diagnosed eye clinic patients may result in the failure to offer access to an ECLO (Hodge, Thetford, Knox, & Robinson, 2015). This was also reported by Boyce, Leamon, Slade, Simkiss, Rughani, & Ghanchi (2014), who found that the responsibilities of an ECLO were often dependent on the consultant ophthalmologists' perceptions of their role. Furthermore, the ECLOs themselves reported being used inconsistently. Inconsistencies in the responsibilities of ECLOs may be a product of them not

being included nationally in NHS service specifications or formal care pathways, despite calls from national bodies, such as the Royal College of Ophthalmologists (RCOphth), the College of Optometrists and the Clinical Council for Eye Health Commissioning (CCEHC), as well as leading sight loss charities, such as the RNIB and Vision UK. Whilst professional accreditation is available to ECLOs, through the University of London, this does not feature among the mandatory requirements of the role.

The absence of ECLOs in the formal NHS care pathway is reflected in the National Institute for Health and Care Excellence (NICE) guidance relating to ophthalmology, in which ECLOs either do not feature or are mentioned peripherally. However, several NICE recommendations for a quality ophthalmology service relate to tasks undertaken by ECLOs, which have been shown to be improved in clinics where an ECLO is in place. Whilst all of the studies referred to thus far have been published within the last ten years, several of these date to the earlier half of this period and, in some respects, are now outdated in light of the rapid growth in ECLO coverage across the UK in recent years. However, many of the issues identified in these illustrate the gaps in service provision that ECLOs are now beginning to fill. They also highlight problems that still warrant attention and make recommendations that remain pertinent.

Are ECLOs effective?

While literature addressing the efficacy of ECLOs is scarce, what does exist reinforces the employment of ECLOs to address several needs within eye clinics. Studies also serve to identify gaps in service provision, with the more recent studies displaying evidence that ECLOs have been successfully addressing these gaps. Three key themes of where ECLOs fill a need, which can be further split into key responsibilities and functions that ECLOs are well-placed to address, can be identified from the literature. These overarching areas are:

- providing emotional and practical support,
- continuity of care, and
- reducing the pressure and burden on eye clinic staff.

Practical support and information

The importance of practical support and information following diagnosis, a core responsibility of an ECLO, is well illustrated throughout the academic literature. Those who were diagnosed prior to the initiation of the ECLO service often reported not being offered further information and support or weren't made aware that a diagnosis of 'nothing can be done' only applied to medical interventions (Thetford, Robinson, Knox, Mehta, & Wong, 2011). This lack of information at diagnosis meant the need for continued monitoring of eye health was not made clear, as evidenced by several of these clinic patients ceasing to have eye tests (Hodge et al., 2015). Whilst the range of time since diagnosis spanned up to several decades in those who were interviewed, thus spanning decades of change and improvement in quality of care, these findings consistently highlight a gap that ECLOs have since been shown to fill, and that NICE guidelines for glaucoma have been updated to reflect. The second phase of the study described here, undertaken three years later, noted that an ECLO service had been established in all of the hospitals used by interviewees and was viewed positively by the participants. However, knowledge of ECLOs didn't always come via the eye clinics. This was particularly the case among those who received their diagnosis prior to the initiation of the ECLO service.

Further evidence to support the employment of an ECLO as an integral part of an eye clinic was garnered from clinical staff, who indicated that they felt safer with an ECLO in position, than compared to pre-ECLO times. Interviews with these staff further reinforced the findings from previous patient interviews, that, historically, further information would not have been provided to patients following diagnosis. Furthermore, this was observed to change following the inception of an ECLO position, which provided clinic staff with a specialised, non-clinical service to which they could refer patients for further support (Llewellyn et al., 2019). ECLOs were described as enhancing the service provided by the eye clinic. Moreover, interviews undertaken by the RNIB with a small sample of ophthalmologists highlighted the importance of face-to-face contact with ECLOs, who were able to provide support and information which could not be achieved through the provision of simple patient leaflets, which rapidly become outdated (Chattaway & Heath, 2015).

Emotional support

At present, a national framework for emotional support for people with sight loss has not been produced (Pybis et al., 2016), and the absence of a minimum standard of emotional support from services is reflected in the literature, particularly among those diagnosed with vision impairment prior to the establishment of ECLOs (Thetford et al., 2011; Thurston, Thurston, & McLeod, 2010). Although these findings were reported in interviews conducted 10 or more years ago, they are echoed in more recent studies, in which clinical staff reported a lack of time to cater to the emotional needs of patients receiving what can often be upsetting diagnoses (Chattaway & Heath, 2015; Llewellyn et al., 2019). These more recent studies report this gap in service provision is actively addressed by ECLOs. From the patients' perspective, interaction with an ECLO significantly increased their emotional wellbeing (Singh, 2013). Interestingly, interviews with clinical staff did not identify any negative effects of ECLOs taking over the emotional support role, such as deskilling in this area; instead, ECLOs were praised as enhancing this offer (Llewellyn et al., 2019).

Continuity of care

Most people, when first diagnosed with visual impairment, are unlikely to have much knowledge of the services and support available to them, nor how to find out about or access these. This is where an ECLO steps in, to guide patients dealing with what can often be a distressing diagnosis toward services that can improve their quality of life. The need for someone to take on this informational and signposting role is shown in interviews with people first diagnosed pre-ECLO, who reported leaving the clinic without any further information on how to adapt to sight loss nor referrals to services that could help them do this (Thetford et al., 2011; Thurston et al., 2010). More recently, staff in clinics who don't have an ECLO report struggling to give this non-clinical – yet still specialised – advice to patients, a point reinforced by other eye clinic staff reflecting that, prior to having a ECLO, there wasn't capacity to develop and maintain sufficient knowledge of the local services to be able to signpost patients towards (Llewellyn et al., 2019).

Furthermore, the support available for visually impaired people can change over time, particularly in terms of local provision; as noted by ophthalmologists in interviews undertaken by the RNIB, having someone who is able to maintain an up-to-date knowledge of services

and support groups is essential, rather than relying on clinicians or leaflets with information that may be out of date (Chattaway & Heath, 2015).

In undertaking the responsibility of developing and maintaining this knowledge of the local landscape of services, ECLOs take the pressure off clinical staff otherwise laden with these duties and give better outcomes for patients, as shown by the responses to a quantitative question completed by people with sight loss, 2-3 months post seeing an ECLO. Nearly half of respondents reported an increased income from welfare benefits, or an intention to explore this option, and third reported increased uptake of services, or intention to do this (although it must be noted, as with each of the reported studies, this study had no control group to compare outcomes against) (Singh, 2013).

Certification and registration of visual impairment

The processes of certification of visual impairment (CVI) and subsequent registration appear in numerous studies as an important gateway for patients to access financial, practical, emotional and social support services, and is much valued by people with sight loss as this stepping stone (Thetford et al., 2011; Boyce et al., 2014). However, certification can be beset with delays, variability in the stage of treatment patients are certified, and lack of follow-up. The processes of certification and registration – reportedly confused by almost all interviewees in a 2014 qualitative study with health and social care professionals and patients (Boyce et al., 2014) – are as follows: the form requesting certification of either sight impairment or severe sight impairment is signed off by an ophthalmologist and, with the permission of the patient, can be shared with the local authority who can then register the person with sight loss. Registration, a voluntary step, is not essential to access support from social services, but is necessary to access some benefits and concessions (Department of Health, 2017). The NICE Quality Standard for Serious eye disorders (2019) reinforces the importance of timely certification and recommends that service providers have systems in place to provide information on the support, services and benefits accompanying certification.

Despite guidance from the Department of Health, which advises that, with the patient's permission, a copy of the certificate should be sent on to the local authority within five working days of its completion, studies report this sharing taking far longer (up to a year in some cases), prior to the addition of an ECLO to the eye clinic (Boyce et al., 2014; Llewellyn et

al., 2019). Reasons for these delays include workload, delays in completion of the forms by ophthalmologists and sending forms off in batches. Similarly, social services staff report incorrectly completed CVI forms, which have to be returned to the hospital, as a barrier to registration and thus access to services (Boyce et al., 2014).

ECLOs, however, were found to take ownership of the process, and improved service quality by streamlining and keeping track of the process. As told by interviewed clinic staff where an ECLO was in place, ECLOs explained the process and benefits of certification to patients, helping them to fill out the paperwork and answering their questions, and ensured certification requests were correctly completed by ophthalmologists and followed through to ensure timely completion (Chattaway & Heath, 2015; Llewellyn et al., 2019).

Joining up care pathways and processes

In the Department of Health guidance for ophthalmologists, having ECLOs in hospitals is recommended as good working practice, to create a link between health and social care and enhance joined up support for the patient (Department of Health, 2017). The effectiveness of ECLOs in this continuity of care role is shown in interviews with social care staff; ECLOs reportedly supported Rehabilitation Officers (ROVIs) to increase patient engagement with them (explaining away the 'stigma' attached to referral to social services seen in some patients), jointly worked with social services to triage patients who needed immediate support and those who could be more safely placed on a waiting list, and followed up certification requests to ensure they happened in a timely manner (Llewellyn et al., 2019).

ECLOs are also shown to fill the need for follow-up and a point of contact post-diagnosis; the lack of follow-up for people diagnosed pre-ECLO meant they were often not made aware of changes or improvements to treatments or services, and changes in their clinical and non-clinical needs were often not identified. Patients who had access to an ECLO, however, reportedly found the ECLO helpful and began to develop ongoing relationships with them (Thetford et al., 2011).

Additionally, clinical staff described ECLOs as providing more of a "complete service" within the eye clinic itself, to whom busy clinical staff could refer patients for further support as the next step in their care, rather than providing a diagnosis then no further information or support. ECLOs were also found to be trusted by clinical staff to support patients in the long

term and, as above, acted as a point of contact for patients, which clinical staff viewed as a significant improvement to continuity of care within the clinic (Llewellyn et al., 2019).

ECLOs as a “bidirectional bridge”

ECLOs placed within hospital eye clinics have been praised by staff who benefit from their close proximity. Indeed, one interviewed ophthalmologist noted that it can be frustrating when the ECLO is not around, when they are unable to refer patients to someone with specialised knowledge of services and capable of supporting the next step in patients’ care (Chattaway & Heath, 2015).

Importantly, ECLOs appear to increase the efficiency of eye clinics without compromising the quality of information given; an “interface” between staff, whereby patients needing further support can be referred directly on to the ECLO and, equally, the ECLO can refer patients with clinical questions outside of their understanding back to clinical staff, was reported in interviews with ophthalmologists (Chattaway & Heath, 2015).

Additionally, whilst clinical staff reported not having the time to develop and maintain sufficient knowledge of local services themselves, ECLOs were reportedly proactive in updating the wider clinical team with changes to the local landscape of services available to patients, ensuring a more complete awareness of the care pathway beyond the eye clinic (Llewellyn et al., 2019).

Reducing the pressure and burden on eye clinic staff

The final theme identified in the literature, of lessening the burden on clinical and admin staff in eye clinics under pressure with growing numbers of patients, is the product of ECLOs fulfilling the above key roles. This is evidenced in interviews with a wide range of eye clinic staff, who unanimously reported that ECLOs supported the “smooth running” of the clinic, giving back “time for the trained staff to do what they trained for” – thus providing cost-efficiencies as specialist staff can focus on seeing more patients. Staff reported that ECLOs allowed the clinic to provide more of a “complete service”, improving quality and continuity of care (Llewellyn et al., 2019).

ECLOs reportedly further reduce the demand for clinical time by providing emotional and practical support and information to patients at the point of diagnosis. Interviews with clinical

staff where an ECLO was in place (although, note a very small sample size of five people) reported a reduced need for follow-up appointments, as a result of the ECLO being on hand to provide immediate and ongoing support. Notably, one nurse explained scheduling follow-up appointments, prior to having an ECLO, as a way to “make up for not being able to support [the patients] there and then”, illustrating both a drain on clinical staff’s time and a lack of timely, complete care for the patient (Singh, 2013).

Who do ECLOs support?

The role profile in the RNIB’s ECLO Quality Framework states that ECLOs provide support for people of “*all ages affected by sight loss, and their families and carers*”, indicating ECLO service provision should be accessible regardless of age, condition or how far along a person is in their care or treatment. However, in the absence of a nationally recognised service specification or NHS pathway, differences in how readily patients can access an ECLO are shown in the literature.

Inconsistency in access

Whether or not an ECLO is fully utilised can vary depending on how clinical staff understand the function of an ECLO or understand the processes in which ECLOs play a role. For example, the timing of certification of visual impairment, a form which ECLOs process and provide emotional and practical support to the patient around this significant step-change in care, can vary by the ophthalmologist doing the certifying and is viewed by many ophthalmologists as the “final stage” in treatment (Boyce et al., 2014), despite Department of Health and NICE guidelines recommending certification as soon as patients are eligible (Department of Health, 2017; NICE, 2019). Indeed, a recent study analysing meetings of all RNIB-funded in the UK found that nearly half of patients seen by ECLOs were not yet certified as sight-impaired (Papastefanou et al., 2020). Whilst access to an ECLO is not exclusive for those receiving certification (and these people could well have simply been not yet eligible for a CVI), this finding could reflect ophthalmologists only referring to ECLOs at the point of certification and not necessarily at the time when an ECLO could have first proved beneficial.

Similarly, the above discussed study also found that half the patients were seen by an ECLO 13 to 18 months post-diagnosis (and a further 19.8% after 18 months). Whilst the reasons for the timing of meetings with the ECLO weren’t given (and could reflect patient-choice or long

waiting lists, rather than clinicians waiting to refer patients), the long delays between diagnosis and meeting the ECLO may have left patients unaware of support services available to them and left possible decline in the emotional wellbeing of patients unmitigated (numerous studies show a link between visual impairment and poor mental health, such as higher prevalence of depression (Nollett et al., 2016)). Differences in how ophthalmologists perceive the role of ECLOs in the eye care pathway may therefore mean that not all people who could benefit from an ECLO are referred to them in a timely way.

Additionally, the timing of first diagnosis may affect access to an ECLO. A two-phase study interviewing people who had had sight loss for at least three years (ranging from three to 79 years; and last visit to an ophthalmologist ranging from a few weeks prior to 37 years) showed, as you would expect, that those who were recently diagnosed were more likely see an ECLO and benefit from follow-up from the eye clinic post-diagnosis (Thetford et al., 2011; Hodge et al., 2015). Yet, those who had been first diagnosed prior to the establishment of ECLOs, and had received no follow-up at the time, continued to remain 'out of the system', and thus without the benefit of up-to-date onward referral to support services or regular monitoring of eye health. These studies reinforce the benefit of ECLOs for those who are newly diagnosed, but highlight the ongoing inconsistencies in care for people who have been living with sight loss for several years; those who weren't offered the option of an ECLO, in the most part due to diagnosis prior to the advent of ECLOs, remained without this option.

Moreover, there was a perception amongst people who had been living with sight loss for a long time and who were aware of ECLOs, that ECLOs were only for the newly diagnosed, rather than being accessible at any point following diagnosis (Hodge et al., 2015). This stands in contrast to the fact that the support needs of patients change over time, as they adapt to sight loss or their vision changes, and that patients may not necessarily be ready to take in or accept information at the point of diagnosis (Thetford et al., 2011).

For ECLOs to be effective, clinical staff must be made aware of the breadth of activities that ECLOs can undertake, and must engage with and champion them, ensuring patients are likewise informed of their availability and benefits (Chattaway & Heath, 2015; Hodge et al., 2015). Moreover, to ensure that the benefits of ECLOs are felt by all people with sight loss, regardless of time of diagnosis or certification, and to ensure that people diagnosed prior to ECLOs are given the opportunity to be brought back into the health and social care support

system, efforts should be made to ensure there is general awareness of the existence of ECLOs, and that, in line with recommendations made by the RCOphth and College of Optometrists (RCOphth & College of Optometrists, 2013), there are multiple opportunities to access ECLO support, not only at first diagnosis.

Service provision for children and young people

ECLOs are intended to serve both adults and children experiencing sight loss. Importantly, visually impaired children have different needs from adults – as discussed in the CCEHC's Low Vision, Habilitation and Rehabilitation Framework for Adults and Children (2017), successful transition to an independent adulthood depends on developing fundamental skills, including mobility, learning and everyday living – which require a comprehensive and integrated pathway between healthcare, social care, education and rehabilitation services. ECLOs, in their bridging role, appear to be well placed to support these links between services; however, the specific knowledge of the referral pathways and services available to children may warrant an ECLO solely for children, dependent on the need (for example, a ECLO dedicated to the needs of visually impaired children is employed by the Paediatric Ophthalmology service in the Belfast Health and Social Care Trust (Chattaway & Heath, 2015)).

Of the studies reviewed here, only one looked specifically at services for infants and children (Boyce, Dahlmann-Noor, Bowman, & Keil, 2015). Interviews with health and social care professionals and parents of visually impaired infants and children found that ECLOs provided a reliable referral route towards social services support and were valued by parents, reflecting the findings of studies addressing eye care pathways for adults. However, referrals to ECLOs were not consistent, relying on the judgement of an ophthalmologist – again reflecting services for adults – and highlighting the absence of a formal mechanism for referrals for children.

Whilst the paucity of studies addressing ECLO provision for infants and children may reflect these people being a significantly smaller proportion of those with a visual impairment, it does represent a gap in the literature addressing the efficacy and best practice of ECLOs for this subset of patients.

Policy context

The NICE Quality Standard for Serious eye disorders (2019) states that patients should be given a certificate of visual impairment (CVI) as soon as they are eligible and that service providers should have systems in place to give information about the support, services and benefits associated with CVI.

Similarly, the NICE guidelines for Glaucoma (2017) state that patients should be given the opportunity to discuss diagnosis, referral, prognosis, treatment, and discharge. It specifically mentions that patient information should refer to ECLOs, whilst the NICE guideline for age-related macular degeneration (AMD) recommends that consideration should be made for the referral of people with AMD to low vision services (NICE, 2018).

ECLO advocates

Contrastingly, the Department for Health guidance for CVI (2017) does endorse ECLOs, stating that it is:

“good working practice to have ECLOs in hospitals as this helps to create a good link between health and social care and enhances joined up support for the patient”.

In line with the Department of Health, the CCEHC states that ECLOs are:

“key in linking patients to services... and understanding impact of their diagnosis”

They further argue that ECLOs should be included in contracts and service specifications, to maximise an integrated care system (CCEHC 2016; CCEHC 2017). Indeed, in the CCEHC’s System and Assurance Framework for Eye Health (2018), ECLOs are specified as part of the onward pathway from hospital eye services, providing the link to Low Vision, Habilitation and Rehabilitation Services (LVHRS). Further backing the inclusion of ECLOs in the ophthalmology pathway is the RCOphth, who advocate for the inclusion of ECLOs in ophthalmology pathways, stating that they consider ECLOs to be:

“a core patient service, with a dramatic impact on patients’ quality of life”

Moreover, the RCOphth takes the view that the ECLO service should not be reliant on charity funding, calling on the NHS to support deployment and funding of an ECLO service in all hospital eye clinics (RCOphth, 2019). The RCOphth further endorse ECLOs as a key player in developing efficiencies across pathways, noting that ECLOs are well-placed to increase capacity in hospital eye clinics by taking on some of the low-risk activities, such as onward referrals and follow-up, thus maximising the use of consultants' time and expertise (RCOphth, 2017; RCOphth & the College of Optometrists, 2019). This view is supported by the Getting It Right First Time Programme (GIRFT, 2019), which noted the importance of multidisciplinary teams in hospital eye services in their Speciality Report into ophthalmology. They also endorsed ECLOs as an important player in

“enabling patients to navigate the [ophthalmology] pathway and attend services appropriately”.

Demand for ECLO services

As discussed, a significant benefit of ECLOs is in taking pressure off clinical staff, particularly in terms of time spent doing non-clinical work, including admin and providing emotional support and practical information to patients. This role will only increase in importance as the demand for ophthalmology services increases. Already the busiest outpatient attendance (ophthalmology departments in England had 7.9 million attendances in 2019-2020 (NHS Digital, 2020)), the need for ophthalmic care is set to increase ever greater as the proportion of older people in the UK's ageing population grows. As recommended by the RCOphth and the College of Optometrists (2019), as this demand grows, greater efficiency can be found in strategic sharing of this burden across multi-disciplinary teams; as shown here, ECLOs have been found to play a prominent role in alleviating pressure on both clinical and admin staff, streamlining processes and having the capacity to navigate often complex pathways between healthcare, social care and voluntary sectors, and ensuring continuity of care for patients.

Activity and costing

Given the complex nature of the intervention and the multiple outcomes being sought, assessing cost effectiveness is difficult. One simple approach was identified in the literature, which has been crudely set out to local data below:

- During the year 2019/20, the WSHT received a total of 588 referrals.

- Of these referrals, 289 (49%) were formally registered as visually impaired.
- It is not clear if the remaining 299 patients were seen by the ECLOs and deemed not currently eligible to register, or if they simply declined, or did not attend, their ECLO appointment.

In 2013, (Gillespie-Gallery et al., 2013) conducted a micro-costing exercise. Based on a salary of just over £23,000 per year, and incorporating setup costs and overheads, they calculated that, assuming nine patients were seen each day, the cost per patient contact was £17.94.

Using these assumptions if all 588 referred patients were seen, this equates to £10,549 over the course of a year (at 2013 levels).

Depending on experience and level of qualification, an ophthalmologist can expect to earn between £40,000 to £75,000 (2013 assumption). Comparing this to the ECLO salary at 2013 levels of £23,000, one might expect that each patient contact with their ophthalmologist will cost the trust £31.22 to £58.48. With the level of ECLO referrals outlined above, if the ophthalmologist were to undertake the tasks conducted by the ECLOs, this could, potentially, cost somewhere in the region of £18,357.36 to £34,386.24 which would indicate that moving tasks away from the ECLO would be more costly. Furthermore, the evidence outlined above would seem to support the assertion that ECLOs provide a significant degree of practical and emotional support which may, in turn, result in significant savings, in terms of depression, suicide and falls prevention.

References

- Blind, R. N. I. f. t. (2019). *Information and guidance for eye clinic staff*. Retrieved from <https://www.rnib.org.uk/eyeclinicstaffguidance>
- Boyce, T., Leamon, S., Slade, J., Simkiss, P., Rughani, S., & Ghanchi, F. (2014). Certification for vision impairment: researching perceptions, processes and practicalities in health and social care professionals and patients. *BMJ Open*, 4(4), e004319. doi:10.1136/bmjopen-2013-004319
- Boyce T., Dahlmann-Noor A., Bowman R., Keil, S. (2015). Support for infants and young people with sight loss: a qualitative study of sight impairment certification and referral to education and social care services. *BMJ Open* 5, e009622. doi:10.1136/bmjopen-2015-009622
- Browne, M. (2003). The nurse's role in helping patients cope with sight loss. *Nursing times*, 99(48), 30-32. Retrieved from <https://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=emed8&AN=38346115>
- <https://4223645.odslr.com/resolver/full?sid=OVID:embase&id=pmid:14705546&id=doi:&issn=0954-7762&isbn=&volume=99&issue=48&spage=30&pages=30-32&date=2003&title=Nursing+times&atitle=The+nurse%27s+role+in+helping+patients+cope+with+sight+loss&aulast=Browne&pid=%3Cauthor%3EBrowne+M.%3C%2Fauthor%3E%3CAN%3E38346115%3C%2FAN%3E%3CDT%3EReview%3C%2FDT%3E>
- Chattaway, T. & Heath, H. (2015). *Sight loss advisers: supporting patients and eye departments*. RNIB. Available from: https://www.rnib.org.uk/sites/default/files/Sight_loss_advisers_supporting_patients_in_hospitals_report_May2015.pdf [Accessed 07/12/2020].
- Clinical Council for Eye Health Commissioning (2016). *Primary Eye Care Framework for first contact care*. Available from: <https://www.college-optometrists.org/uploads/assets/8a93d228-ac28-4e6e-98af94c62c0f8442/Primary-Eye-Care-Framework-for-first-contact-care.pdf> [Accessed 07/12/2020].
- Clinical Council for Eye Health Commissioning (2017). *Low Vision, Habilitation and Rehabilitation Framework for Adults and Children*. Available from:

<https://www.college-optometrists.org/uploads/assets/2642d67c-96f9-4e12-ab4c402b2df4e15c/Low-vision-habilitation-and-rehabilitation-framework-for-adults-and-children.pdf> [Accessed 07/12/2020].

Clinical Council for Eye Health Commissioning (2018). *System and Assurance Framework for Eye-health (SAFE) – Overview*. Available from: <https://www.college-optometrists.org/uploads/assets/2d2e4368-07f8-47b8-80cd3f429abea251/SAFE-Overview.pdf> [Accessed 17/12/2020].

Department of Health (2017). *Certificate of Vision Impairment Explanatory Notes for Consultant Ophthalmologists and Hospital Eye Clinic Staff in England*. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/637590/CVI_guidance.pdf [Accessed 07/12/2020].

Gillespie-Gallery, H., Subramanian, A., & Conway, M. L. (2013). Micro-costing the provision of emotional support and information in UK eye clinics. *BMC Health Services Research*, 13, 482. doi:<https://dx.doi.org/10.1186/1472-6963-13-482>

GIRFT, MacEwen C., Davis A. and Chang, L. (2019). *Ophthalmology GIRFT Programme National Specialty Report*. Available from: <https://gettingitrightfirsttime.co.uk/wp-content/uploads/2019/12/OphthalmologyReportGIRFT19P-FINAL.pdf> [Accessed 07/12/2020].

Hodge, S., Thetford, C., Knox, P., & Robinson, J. (2015). Finding your own way around: Experiences of health and social care provision for people with a visual impairment in the United Kingdom. *British Journal of Visual Impairment*, 33(3), 200-211. doi:10.1177/0264619615596198

Llewellyn, M., Hilgart, J., Joshi, P., & Williams, A. (2019). Impact of eye clinic liaison officers: a qualitative study in UK ophthalmology clinics. *BMJ Open*, 9(3), e023385. doi:10.1136/bmjopen-2018-023385

National Institute of Health and Care Excellence (2017). *Glaucoma: diagnosis and management (NICE guideline 81)*. Available from: www.nice.org.uk/guidance/ng81 [Accessed 07/12/2020].

National Institute of Health and Care Excellence (2018). *Age-related macular degeneration (NICE guideline 82)*. Available from: www.nice.org.uk/guidance/ng82 [Accessed 07/12/2020].

- National Institute of Health and Care Excellence (2019). *Serious eye disorders (NICE Quality Standard 180)*. Available from: <https://www.nice.org.uk/guidance/qs180> [Accessed 07/12/2020].
- NHS Digital (2020). *Hospital Outpatient Activity 2019-20*. Available from: <https://digital.nhs.uk/data-and-information/publications/statistical/hospital-outpatient-activity/2019-20/summary-report---treatment-specialities> [Accessed 14/12/2020].
- Nollett, C.L., Bray, N., Bunce, C., Casten, R.J., Edwards, R.T., Hegel, M.T., Janikoun, S., Jumbe, S.E., Ryan, B., Shearn, J. and Smith, D.J. (2016). High prevalence of untreated depression in patients accessing low-vision services. *Ophthalmology*, 123(2), 440-441. <https://doi.org/10.1016/j.ophtha.2015.07.009>
- Papastefanou, V. P., Kang, S., Simkiss, P., & Zambarakji, H. (2020). Eye clinic liaison officers service in the United Kingdom. *International Journal of Health Planning & Management March*, 35(2), 506-519. doi.org/10.1002/hpm.2938.
- Pybis, J., Thurston, M., Dennison, C. M., Broom, M., & Miller, A. (2016). The nature of emotional support and counselling provision for people with sight loss in the United Kingdom. *British Journal of Visual Impairment*, 34(2), 167-176. doi:10.1177/0264619616633884
- Royal College of Ophthalmologists (2017). *The Way Forward*. <https://www.rcophth.ac.uk/wp-content/uploads/2015/10/RCOphth-The-Way-Forward-Executive-Summary-300117.pdf> [Accessed 07/12/2020].
- Royal College of Ophthalmologists (2019). *Eye Clinic Liaison Officers (ECLOs) are vital to supporting patients with sight loss*. Available from: <https://www.rcophth.ac.uk/2019/03/eye-clinic-liaison-officers-eclos-are-vital-to-supporting-patients-with-sight-loss/> [Accessed 30/11/2020].
- Royal College of Ophthalmologists and College of Optometrists (2013). *Commissioning better eye care: Adults with low vision*. Available at: https://www.rcophth.ac.uk/wp-content/uploads/2014/12/Low-vision-guidance-25-11-13-2013_PROF_263.pdf [Accessed 07/12/2020].

- Royal College of Ophthalmologists and The College of Optometrists (2019). *Ophthalmic Services Guidance – Primary Eye Care, Community Ophthalmology and General Ophthalmology*. Available at: <https://www.rcophth.ac.uk/wp-content/uploads/2019/02/Primary-Eye-Care-Community-Ophthalmology-and-General-Ophthalmology-2019.pdf> [Accessed 07/12/2020].
- Singh, S. P. (2013). *Economic Impact of an Eye Clinic Liaison Officer (ECLO) on Health and Social Care Budgets: A Case Study*. RNIB. Retrieved from London:
- Subramanian, A., Gallery, H. G., & Conway, M. L. (2012). The role of the Eye Clinic Liaison Officer (ECLO) - A diary study. *Investigative Ophthalmology & Visual Science*, 53(14), 4407-4407.
- Support, S. V. (2020). Sight Care Advisor. Retrieved from <https://www.4sight.org.uk/sight-care-advisors/>
- Thetford, C., Robinson, J., Knox, P., Mehta, J., & Wong, D. (2011). Long-term access to support for people with sight loss. *British Journal of Visual Impairment*, 29(1), 46-59. doi:10.1177/0264619610387889
- Thurston, M., Thurston, A., & McLeod, J. (2010). Socio-emotional effects of the transition from sight to blindness. *British Journal of Visual Impairment*, 28(2), 90-112. doi:10.1177/0264619609359304

APPENDIX 3 – Sensory Impairment Views and Experience – Service users, Carers and Families (Draft Summary)

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Full report: Healthwatch (April 2021). *Local people's experiences of services and living with sensory impairment engagement*

Acknowledgements

This is a summary of the work undertaken and includes some caveats, as we know that further engagement and sense checking of comments made will be needed as an important part of supporting changes at a local level.

We have drawn out comments which highlight specific concerns, good practice and/or were frequently made.

We would like to thank the people who provided their views and experience, and we acknowledge the considerable difficulties in conducting engagement during a lockdown of the COVID-19 pandemic and we specifically thank Healthwatch West Sussex, RNIB and 4 Sight in leading this work.

It is important to recognise that this represents engagement collated where visual impairment was the core focus. It is recommended that further work be undertaken in relation to hearing impairment and dual impairment, and more detailed work will be required in relation to children and young people.

Who took part in the engagement

Central to the needs assessment was to find out the day-to-day experiences of service users and service providers.

This was achieved through an engagement process which included three elements:

- Four surveys of service users (130 responses)
- Four focus groups of services users (53 participants)
- One survey of service providers (16 responses)

Visual impairment

The findings in this section are based on the following:

- Survey of adults with visual impairment (77 responses).
- Children and young people with visual impairment (13 responses).
- 4Sight Vision Support held three virtual focus groups with members living or supporting someone with visual impairment between December and February 2021 (25 participants).
- Healthwatch joined the Macular Support Group Midhurst telecall in December 2020 (7 participants).

Survey of adults with visual impairment

The respondents

- 77 people completed the survey.
- Diagnosed between birth and 84 years of age.
- 81% registered as having a sight impairment.
- Diagnosis:
 - 55% diagnosed at an NHS hospital.
 - 26% diagnosed at an optician.
 - 12% diagnosed at a High Street optician (such as Specsavers, Boots).
 - 5% diagnosed by GP.

Respondents' main worries when diagnosed fell into the following areas:

- Emotional (timescales, effect of blindness, working, effect on independence, confidence).
- Social (reading, phone numbers, watching TV, getting around – public transport, driving).
- Physical (getting around and navigating outside the home, coping with life and dependents).
- Information provision.
- Support.
- What was needed.

Many respondents shared that they felt overwhelmed by the diagnoses and were left without appropriate support or explanation. People questioned who can support their emotional outcomes of depression, isolation, and increased disability.

Some people said that they were left without the right information, awareness of treatment options and future support, which affected their acceptance of the condition, control, confidence, motivation, and self-worth.

Some reported feeling silenced by clinicians' tone of communication and not acknowledging their distress.

Whether there was sufficient support in place to address people's worries

More than half of respondents said there was **insufficient support** in place to address their initial concerns after diagnoses.

Information that was received specific to sight loss

- Over three quarters of respondents said that they received no support for the **emotional aspects** of living with sight loss.
- Half of respondents stated that they received no support with **day-to-day living needs**.
- Half received no **information about the condition** and what happened next.
- Half did receive **support with various aids** to help support day-to-day living.

Beyond the original diagnosis, information that was received was stated as follows:

- On the visual aids available to help you with your condition (65%)
- Physical condition and what will happen to your sight (47%)
- On supporting your day to day living (39%)
- On supporting your emotional wellbeing (23%)

Of those who received information:

- 56% said that they did not have any opportunity to discuss this.
- 57% said that they received information only about the various aids available.
- 70% said that they did not receive any information or support for the emotional aspects of living with sight loss.
- 57% said they received some information and support for day-to-day living.

If information received, were there opportunities to have this explained to you or to receive further information, if needed?

Respondents were most likely to have the opportunity to have the information received explained further around the visual aids available and their condition and what happens next. They were less likely to have the opportunity to further discuss support for daily living and emotional wellbeing.

Comments suggest that receiving timely information and support could help with both the physical aspects of coping with sight loss as well being able to continue doing many of the things that people did before their diagnosis such as working.

The answers suggest there is a need to look at how services can further support people to come to terms with their sight loss, including the need for emotional support, and how this affects their daily living.

How visual impairment has affected people's daily lives

Three-quarters of respondents (58 people) said their sight loss has left them feeling isolated and socially excluded.

Respondents informed that everyday life is difficult, and they had to adapt continuously. Several people reported that they had lost the ability to read and write. Some needed gadgets and technology to help with everyday tasks but also help to get these items and learn how to use them.

Answers suggested that sight loss is socially isolating and has made everyday tasks more difficult.

Access to community groups to help people with a visual impairment feel less isolated

More than half of respondents (43 or 56%) said they had accessed various community organisations.

Confidence in communicating with others

Almost all respondents (75 of 77) felt confident in communicating with others.

Support services for people with a visual impairment

Not all people were offered any support. But of those who were, **NHS/hospital services (30%) and voluntary and community organisations (28%) are the main support** providers that people diagnosed with a visual impairment noted. Other providers of support included opticians on the High Street (13%) and local authorities (10%).

People were generally happy with the quality of the services provided (52% said services were good or very good) and found service easy to contact (50% said services were easy to contact).

Meanwhile, **the main issue for people was physically attending** the services with only 25% describing this as good or very good.

Respondents' preferred methods of contacting services

- Telephone (34%)
- In person (21%)
- Email (16%)
- Text message (10%)

Further needs and support

Support tools

Various support tools were listed in the survey and respondents asked whether they used them and found them useful. These were mobile apps, voice recognition software, Braille keyboard and screen reader. Most were not used to any significant extent.

The most frequently used were mobile apps (27%), voice recognition (25%) and screen readers (17%).

Unsupported needs

Various unsupported needs were mentioned by respondents. These tended to be individualised and included training for using technology and issues around prescriptions.

Other issues with healthcare were noted such as lack of advice on eye health, issues around diagnosis in terms of explanation and appropriate support from the GP or healthcare professional.

Additionally, concerns were expressed about overdue check-up and follow-up appointments as well as operations and procedures.

Other long-term conditions or disabilities

More than six in ten respondents (64%) live with another long-term condition.

Covid-19 pandemic

The rules and guidelines that became central to the government's response to the pandemic had many **negative consequences**. In particular, the independence that people had built over time has been lost and established communication methods changed.

For some, the wearing of facemasks has made communications more difficult due to 'hiding' visual cues.

Transport issues were also highlighted – community transport closed, and social distancing and seating issues on buses and trains were noted.

There were delays to appointments, or virtual alternatives, and the loss of direct GP services. This caused issues and deterioration in eye health.

The changes affected some people's mental health making them feel more anxious, more vulnerable, and more socially isolated due to support groups closing.

Some **positive consequences** were noted by respondents. Social distancing helped in enclosed spaces, virtual groups, calls and newsletters replaced face-to-face meetings, and some noted they were able to relax and do things at home. Some said they were happy with virtual and telephone alternatives to traditional appointments.

Survey of parents of children and young people living with visual impairment

The respondents

- 13 parents/carers of children with a visual impairment completed the survey.
- Diagnosed between birth and five years of age.
- Main cause for visual impairment:
 - Congenital Cataract (7)
 - Brain Haemorrhage (2)
 - Genetic condition (2)
 - Encephalitis and sepsis from a viral infection.
 - Abnormalities unknown
- 9 children also had another impairment or disability, including 3 with a hearing impairment.

Main worries or concerns

- How would this impact on his life?
- The difficulties associated with this.
- What if the surgery went wrong?
- The future and impact on education.
- Do teachers have enough training or resources?
- How the visual impairment affects balance, etc.

Support available to address parents' concerns

- Parents felt they had to make up for lack of service provision.
- Uncertainty about the future.
- Lack of knowledge about how support child/parent.
- Lack of practical support (e.g. to get to appointments).

Eight of the 13 parents said there was not enough support to address their concerns.

- Expense and practicalities of travelling to Great Ormond Street Hospital.

Support for visual impairment in mainstream schools

- Support for children with a visual impairment was described as 'poor' which affected the children's education.
- Parents suggested that training could be made available for teachers (e.g. print size and helpful colours).
- Support at school hit and miss (particularly primary).
- EHCP made but not always followed.
- Concerns not always listened to.
- Post hospital support prior to diagnosis not offered.
- Regular testing not happening.

Support services

Outside the family, most support comes from:

- NHS services (10).

- School (10).
- Voluntary organisations (7).
- LA/council (3).
- Others (3).

The overall experience of using support services

Based on the response, although people's experiences of using support services were mixed, in the main they were rated as good.

The overall experience of using support services

	1 Very poor	2	3	4	5 Very good
Quality of service	1	1	2	5	3
Ease of contacting the service	2	0	3	4	2
Ease of physically attending the service	1	1	3	4	2
Improvement in wellbeing from these services	0	2	2	2	4

Services reported as working well were:

- Hospital eye clinic.
- Brighton eye clinic.
- Cardiff eye Clinic.
- Sensory support and PACSO.
- Local opticians.
- 4Sight Vision Support and RNIB.
- Guide Dogs for the Blind.
- Look Sussex, Blatchington Court Trust and Chailey Heritage Trust.
- Voluntary organisation outside West Sussex.

Services not working so well/not useful

- Access to services and knowing where to go.

- Level of disability to qualify for support (not impaired enough).
- No support until diagnosis.
- Issues with continuous support.
- Gaps in education
 - No primary school with VI unit.
 - Dedicated staff (QTVI) lack comprehensive/specific knowledge of VI conditions.
 - Generic advice only from QTVI.
- Too few community opticians for special needs children.
- Generally, it was felt that the regular ophthalmology/NHS could be better, have better communication, and better services, as currently there is a lack of service provision.

Support and information needed

- Information about services available for sight impairment.
 - Information about charities able to help.
- Condition-specific support.
- Primary school with VI unit.
- QTVI trained in specific conditions.
- Advice and resources for schools.
- Automatic supply of two pairs of glasses.
- More funding for staffing.
- Support network for VI children.
- More day care providers.
- Town centre redesigned with VI in mind (Chichester), such as pavement layout, dog mess, overgrown bushes, etc.

Connecting to non-medical organisations

Around half of the respondents had not been informed about non-medical organisations which might be able to provide support.

Communicating with others

Eleven of the 13 parents said their child felt confident in communicating with others.

Only a few of the 13 parents reported using aids/tools/technology to assist communication:

- Mobile app (4)
- Screen reader (2)
- Voice recognition software (1; a further 3 used this but did not find it helpful)
- Braille keyboard (1)

Other items used included: audio reader and a Kindle, iPad, magnification to enlarge font for writing and TV screen, Monocular, walking cane, wireless keyboard.

Ideas to improve communications

- Consider emotional aspects of visual impairment.
- Professionals should introduce themselves.
- Patience and time.
- Children and adults begin taught about visual impairment.
- Children should not have to explain impairment to everyone.
- Improved spaces such as signage, safe paths, trained bus drivers.
- Support to make technology more accessible.
- Not all children respond verbally.

Further support needed

Five of the 13 parents said their child had needs which were either unsupported or could be better supported:

- Anxiety help and advice.
- One-to-one support to attend clubs (it was stated that none were available).
- Home schooling equipment and advice.
- Taking part in sports – support, time of day and distance.
- Vocational support (e.g. touch typing).
- Getting to services – transport and routes.

- Support with technology for communication and play.
- Information about the roles of professionals.

Covid-19 pandemic

The pandemic had wide-ranging consequences for the parents and their children.

- Appointments delayed or cancelled:
 - Hospital
 - Ophthalmology
 - Assessments
 - Sensory Support Team
 - Mobility Team
- Social impacts such as loss of activities and networks:
 - Visiting friends
 - Support clubs
 - Support networks
- Unable to attend school.
- Social distancing issues (e.g. loss of guides and 24/7 carers)
- Anxiety.
- Impact on parents providing full-time support.

Visual Impairment Recommendations

In reviewing data collected as part of the engagement process, the recommendations are as follows:

The recommendations are made to the Sussex Health and Care Partnership Ophthalmology Transformation Programme Board and to the West Sussex County Council and its Health and Care Scrutiny Committee.

1. The promotion of non-medical services to enhance independence, self-esteem, mental health, and wellbeing should be embedded in all Eye Health Pathways and procurement specifications/commissioning contracts.
2. Make sure that suitable information about the condition and associated support is provided prior to discharge, and/or when a patient is referred to community services. Then they can be more health literate and prepared to benefit from support, which will help them to adapt to changes arising from their condition.
3. When reviewing eye pathways, the commissioning of community services, which can support patients' emotional, psychological, and social needs, and that can work with healthcare professionals, is promoted and made-available to ensure there is a holistic person-centred approach.
4. Transport to and from hospitals and hubs to be included in the Pathway and commissioning arrangements; as visual impairment makes driving or using public transport unsafe, to recognise that people may need additional support.
5. Include community organisations in the transformation workshops to ensure that a wider understanding of need is captured and informs the change processes. This could include a Roundtable webinar for all professionals.
6. The Ophthalmology Programme and West Sussex Stroke Reconfiguration Teams to examine the cross over between their work, to ensure patients who have a visual stroke get prompt access to treatment and support, to achieve better health outcomes.
7. For all services that interface with people with visual impairment. Communications, and associated templates, to be offered in a range of formats to meet different patient needs. At a minimum be appropriate to an audience with reduced ability to see, standard printed material (using at a minimum font size 14, in a simple typeface such as Arial)