# LOCSU Low Vision Pathway Case for Change



#### **BACKGROUND**

The LOCSU low vision pathway is a habilitative pathway designed to enable people with sight loss to make maximum and best use of their remaining eyesight and visual function, thus enabling them to live independently and for longer. The pathway is aligned to the principles of Optometry First in that vision and eye-related concerns should be assessed in primary care and, where possible, managed in primary care, working in partnership with local health and social care services and the hospital eye service. The pathway aims to complement existing secondary low vision services, standardising service delivery in primary care and providing timely and adaptive support that is easily accessible.

The LOCSU low vision pathway is designed to deliver convenient and timely access to specialist low vision care through a network of accredited low vision practitioners in primary care working alongside Eye Care Liaison Officers (ECLOs), rehabilitation officers and third sector partners to provide an integrated care service. Delivering a low vision service which is cost effective and accessible, helping to reduce health inequalities for one of the most vulnerable groups of people in society. The service will also support the release of capacity within hospital low vision clinics, enabling specialists to focus their attention to people with more complex medical conditions that require hospital intervention.

With recent NHS reform and the establishment of Integrated Care Systems (ICSs), it is imperative now more than ever to bring organisations together to deliver integrated health and care services, improving the lives of the population they serve.

# **Epidemiology**

A person is considered to have low vision if they have an impairment of their visual function that cannot be remedied by conventional spectacles, contact lenses or medical intervention and which causes restriction in everyday life <sup>1</sup>. Currently, there are an estimated two million people with sight loss living in England and the number is on the rise<sup>2</sup>. Demographic ageing is leading to a substantial increase in the prevalence of age-related sight-impairing conditions, and associated increases in their costs of care to the NHS, with estimations of £25 billion annually <sup>1</sup>. As the UK population grows and lives longer, the number of people living with sight loss is expected to increase by over a third within the next decade, reaching 2.7 million by 2030 <sup>2</sup>. This escalation is largely due to increasing prevalence in age-related eye conditions that are also the main causes of sight loss e.g., glaucoma and age-related macular degeneration. It is estimated that 79 per cent of people living with sight loss are over the age of 64, while one in three aged 85 and over live with sight loss <sup>2</sup>.

Whilst typically diabetes mellitus has been thought of as a metabolic disorder in middle-aged and older people, of late, the incidence of type 2 diabetes mellitus in the younger demographic (>40 years of age) is rising<sup>3</sup>. This increase in prevalence with its associated considerable morbidity and mortality is a burgeoning public health concern <sup>4</sup>. Specifically, one of the most common complications of diabetes mellitus is diabetic retinopathy, a leading cause of vision loss and blindness in working age adults <sup>5</sup>. It has been reported that around 27% of non-working registered people left their last job due to the onset of sight loss or deterioration of sight, though, more people would stay in employment with the right support such as specialist vision rehabilitation to improve confidence and low vision aids to enable the person to live and work independently for longer <sup>6</sup>.

Similarly, whilst the prevalence of sight impairment in children is low, there has been a greater than two-fold increase in the incidence of blind/severely sight impaired and partial sight/sight impaired in children in England between 1982 and 2019 <sup>7</sup>. This increase may be attributed to an increase in uptake of General Ophthalmic Services (GOS) sight tests in primary care, as well as improved case finding of inherited ocular conditions. Children with low vision are seen routinely under secondary care for their low vision assessments and are typically followed up yearly, although the Covid-19 pandemic has resulted in significant delays for both initial and follow up appointments <sup>8</sup>.

Despite recognition of the importance of eyecare nationally over the last few years, major disparities continue to exist amongst distinct population groups. For instance, factors contributing to sight loss vary by ethnicity: South Asians have a higher risk of cataracts and diabetic eye disease in comparison to other population groups <sup>9,10</sup> and the risk of glaucoma is much higher for the Afro-Caribbean population compared to the Caucasian population <sup>11</sup>. Most notably, the incidence of sight loss is greater in areas of social deprivation. This may partly be attributable to late presentation related to the expense of travel and treatment, as well as general lack of access to prompt and appropriate healthcare or lack of awareness and knowledge of the ocular condition <sup>12,13</sup>. It is, therefore, important to recognise that when planning for low vision services, there may be a higher need and demand within certain patient groups.

#### **Impact on Life**

It is essential to remember that the challenges of sight loss are unique to the person and can be influenced by factors such as onset of sight loss, family, and social support, as well as the cause of the sight loss itself. There are many causes of visual impairment, some of which impact on central and reading vison, others affect the visual field reducing mobility and orientation, and in some cases, patients have a combination of both. Other causes of low vision may be attributed to how people function in different lighting conditions e.g., poor vision in low light levels or due to disability glare.

Importantly, loneliness has long been shown to be a strong predictor of health and quality of life <sup>14, 15</sup>. Historically and more so recently, living with sight loss has resulted in a social epidemic of loneliness and social isolation highlighting the lack of universal accessibility in the environment we currently live in. Limited social networking in combination with general information deprivation has been shown to result in barriers in accessing appropriate health care and support in a timely manner. Therefore, strategies aimed to reduce loneliness could improve life satisfaction amongst those people living with sight loss.

Moreover, living with sight loss can be especially difficult when faced with a reduced capacity to carry out everyday activities. Sadly, only a quarter of partially sighted or blind individuals of working age are in employment <sup>16</sup> and despite disability legislation, exclusion from the workplace due to visual problems is estimated to cost £7.4 billion to the UK economy <sup>2</sup>. As a result of poor and fragmented social and health care, there is a clear functional status decline in community-living people with sight loss <sup>17</sup>.

Furthermore, factors increasing the risk of falls include poor visual acuity and visual field loss, with a three-fold increase in the number of falls in comparison to those who do not have visual field loss. Currently, falls are the most common cause of hospitalisation for people aged over 65 costing the NHS more than £2 billion per year and the costs with a growing and ageing population is only set to increase <sup>18</sup>. In fact, one in three people aged over 65, and half of those aged over 80, fall at least once a year with falls being the most common cause of death from injury in the over 65s <sup>19</sup>. Furthermore, reduced contrast sensitivity was listed as the strongest predictor of increased rates of falls and other injuries and highlighted the importance of contrast sensitivity screening <sup>20</sup>. A 2022 study by Wang and colleagues established that between 40-50% of older people with sight loss limit their activities due to a fear of falling <sup>21</sup>. Non-activity affects muscle strength, which increases the risks of a fall, resulting in a vicious cycle. Many of these individuals may also have additional health conditions which further compromise health and rehabilitation outcomes, including reduced quality of life, disability, increased healthcare costs, increased inpatient admissions and higher death rates <sup>22</sup>.

# **Current Provision of Care and Implications**

Traditionally in England, patients with low vision are managed in secondary care by optometrists, dispensing opticians, or orthoptists in an outpatient setting, with relatively few NHS services available in primary care often working within localised footprints. Additionally, due to the geographically variable nature of the low vision assessment undertaken, some patients have additional support in comparison to others in accessing health and social care resulting in a 'postcode lottery'. Alternatively, whilst private provision of low vision services does exist, the variability in the depth of care and support they each offer differs, which further exacerbates health inequalities for people with sight loss.

Currently, there is significant variation in the waiting times for initial low vision assessments and equally long waits for habilitation. In some parts of England, whilst there are low vision assessments, low vision follow-up appointments are not typically offered, which impacts on understanding long-term outcomes and patient benefit. Where they are offered, there are often significant delays resulting in poor efficacy of the service as the patient often disengages with the pathway. Furthermore, the Covid-19 pandemic has caused delays elsewhere within secondary care in accessing timely treatment for eye disease, thus increasing the proportion of people living with sight loss and so significantly impacting upon the existing low vision services<sup>8</sup>.

Historically, the route to access Sensory Support services is often following patient certification as Sight Impaired or Severely Sight Impaired by a Consultant Ophthalmologist. This often requires a person attending multiple eye hospital appointments over several years and as they pass along the treatment pathway, certification is often offered as a last resort. Therefore, by the time the patient has been referred, they may have been living with their sight loss for years, with their quality-of-life decreasing day by day. It has been demonstrated that early intervention by the sensory service is paramount to identify visual pathways and processes anomalies before sensory outputs are set. Early intervention has been shown to result in a positive emotional setting that enhances the patient's motivation and their relationship with their sight loss <sup>23</sup>. It is therefore crucial that people living with sight loss are diagnosed and referred via an integrated pathway as soon as possible.

Remarkably, there is large cohort of the population living with sight loss who no longer access eye care after discharge from the HES due to a variety of reasons, who are often living with sight loss without practical nor emotional support <sup>15</sup>. Whilst having the choice of attending low vision services is important, patients must still receive the treatment and monitoring of their eye care health to prevent further sight loss. Consequently, the development of more integrated low vision services has significant benefits for patients, practitioners and organisations across health and social care.

Change needs to happen now. Waiting times for ophthalmology appointments are at an all-time high and the current demand on secondary care services, and with an ageing population, this is projected to only get worse. Without action, we as a nation are to face the worsening consequences of the current fragmented low vision provision in England on the quality of life of those who are most vulnerable in society.

# **Service Transformation - Integrated Low Vision Service**

"The primary aim of low vision services is to enable people with loss of vision to regain or maintain as much independence and autonomy as possible. Low vision services achieve this

through a wide range of tools depending on individuals needs including rehabilitation, visual aids, emotional support and advice." (The College of Optometrists, 2013).

The primary aim of the low vision assessment is to provide a flexible, holistic approach in managing sight loss to maximise any residual vision and help to maintain independence. This advice and/or provision of visual aids will have the beneficial effect of enabling independent living in a safe and secure manner aligning with the principles of the NHS Long Term Plan <sup>24</sup>.

Over the past two decades, the concept of low vision care has moved on from provision of magnifiers to a holistic rehabilitation process involving a range of disciplines and professionals. The Low Vision Service Wales (LVSW) was introduced in 2004 following funding by the Welsh government to develop a programme of change in community eyecare in Wales. This programme aimed to 'preserve sight through the early detection of eye disease and to give help to those who have low vision and whose sight is unlikely to improve'. The LVSW is an NHS funded service care model delivered by primary care optometrists and dispensing opticians, existing alongside secondary care. Within the first nine months of the LVSW being rolled out, the wating times for a low vision assessment reduced by 50%, with many patients who were seen in community waiting less than two weeks for an appointment in comparison to six to nine months for a secondary care appointment <sup>25</sup>.

Overall, the LVSW has been a key player in opening the dialogue between multidisciplinary teams, enabling continuity of care and a seamless patient journey. Moreover, it has improved relationships and links between low vision practitioners and visual impairment and rehabilitation teams in local authorities across the nation.

# **LOCSU Low Vision Pathway**

The LOCSU low vision pathway is designed to provide people living with sight loss a user-friendly, streamlined service offered at a time and place convenient for them, their families and/or carers. The pathway encourages easy access to low vision aids (LVAs) and daily living aids to meet patients' individual needs promoting independence and a better quality of life for those people with sight loss. It will encompass an easily accessible, high-quality low vision assessment by trained clinicians in primary care, providing information and personalised clinical advice increasing patient satisfaction and experiences. There will be clear signposting to the low vision service through whichever route the patient accesses, with seamless integration with other local partners supporting those with sight loss. Collaborative working with multidisciplinary teams such as the falls team and sensory support following a low vision appointment is encouraged via referrals, information sharing and signposting. Additionally, the LOCSU low vision pathway allows for self-referral, encouraging people with existing sight loss and who need an assessment to access the service eliminating the barriers that they currently face in accessing care.

The LOCSU Low Vision pathway supports close liaison between optometrists, dispensing opticians, GPs, social services rehabilitation officers, third sector support providers and patients. Most importantly, the collaborative framework helps to bridge the gap between existing primary and secondary care low vision services. The pathway is specifically designed to make best use of the core skills of optometrists and dispensing opticians enabling open channels of communication with rehabilitation officers and third sector partners to provide a fully integrated service. At its core, the low vision pathway enables partnership working to the benefit of the patient through the expertise of those trained in rehabilitation of people living with sight loss.

#### Recommendations

It is vital that a review of existing local provision for low vision services and referral pathways is conducted with a subsequent improvement plan that makes a difference to those people who need it most.

We urge you to work closely with Local Optical Committees (LOCs), Local Eye Health Networks (LEHNs) and Primary Eyecare Companies (PECs) to facilitate an integrated low vision service in primary care that is universally supportive, championing Local Authority goals in aiming to reduce health inequalities and promoting the NHS Long Term Plan to live well and age well.

Supporting out of hospital services in local communities is a fundamental recommendation of the NHS long term plan. By commissioning the LOCSU low vision service, you are recognising the value of the skilled professionals in primary care who can make a difference to patients' lives removing barriers of access to care they currently face. The LOCSU low vision pathway further supports public health outcomes such as increasing healthy life expectancy and reducing inequality of care provision across the nation, especially in lower socio-economic groups that often find it difficult to access healthcare and support.

The LOCSU low vision pathway is designed with patients' needs at its core, meeting demands and evolving with the patients' needs overtime. The pathway offers a solution to long waiting lists, as the patients will be seen sooner and at a location closer to home. As we adapt to working in the newly established Integrated Care Systems, we need to work together to improve health outcomes in public health and tackle inequalities in outcomes, experience, and access. Integrated care cannot happen without collaboration between primary and secondary care and the LOCSU low vision service presents an optimum opportunity to demonstrate how the goals and aims can be met and exceeded by providing care to those living with sight loss.

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