NHS Sussex Sensory Impairment Health Inequalities Summary

4Sight Vision Support and East Sussex Vision Support

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Report written by:

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4Sight Vision Support

Executive Summary

Our Lived Experience Project data highlights significant health inequalities in Sussex.

Particularly for individuals with visual impairment and multimorbidities (the presence of two or more long-term health conditions, which can include both physical and mental health issues) barriers to healthcare access have directly led to worsened health outcomes and decreased well-being.

These barriers, include accessing services, transportation issues, poor communication, navigation, and information.

To address these health inequalities in Sussex requires a multi-faceted approach, focusing on improving communication, appointment scheduling, timely access to visual impairment and mental health services, consistent emotional and practical support, enhanced transportation options, and raising awareness of other appropriate support services.

By implementing our recommendations. NHS Sussex can improve the quality of care and support for individuals with sight loss and the overall patient experience which will significantly improve the quality of care and support for individuals' living with sight loss in Sussex.

Introduction

The aim for the lived experience project was to amplify the voices of blind and partially sighted people across Sussex, by highlighting the health inequalities and barriers to accessing and engaging with NHS services.

This report seeks to identify key issues, barriers, and trends, and provide recommendations to help address these inequalities.

It is important to note; this project was funded by the **NHS Sussex Health Inequalities** Small Grants Fund.

> I recently had a text reminder about an appointment, which was good as I had not received paper notification. But I had to ring to find out what it was for as I don't use my mobile phone much, as I can't see to use it.

Methodology for the project

The data was collected through one-to-one engagement, using a structured survey and interviews with residents of Sussex. The focus was on their experiences of engaging with NHS services, communication of diagnosed condition, and the impact of these conditions on their daily lives. The collected data was analysed to identify key findings and trends.

Challenges

One of the major early challenge and barrier whilst working on the project was the suggested online platform – NHS Sussex Engagement HQ, to be used to collect responses. This was inaccessible for individuals who use screen readers. Once identified, the decision was taken to transfer the survey information to Microsoft Forms. This delayed the launch date of the survey by around 6 weeks.

Another significant challenge was due to a change in digital platform provider by NHS Sussex. This meant that the data collected during February 2024, to May 2024 was lost, as the data had not been backed up prior to the change of provider.

Once the survey went live, we became aware that people sharing their insight over the phone were interpreting some of the questions in a variety of ways. Therefore, the questions were constantly reviewed throughout the project to ensure people were clear on what they were being asked.

Thank you

We would like to thank all people who shared their time with us and their stories.

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Key Findings

Communication

Accessibility and clarity in NHS communications were key concerns. The difficulties around receiving information in preferred formats, paired with complex medical terminology, can create real barriers for individuals living with visual impairment trying to manage their healthcare.

> Accessibility and clarity are interconnected principles for effective communication and content design.

> Accessibility focuses on making information and content available and usable by everyone.

> Clarity ensures that information is understandable, well-organised, and easy to interpret.

> Accessibility and Clarity together, ensure that content is reachable and comprehensible, allowing diverse audiences to engage with it effectively and without barriers.

The preference for digital communication methods like SMS, Email, Telephone, and NHS App is understandable, as these formats offer convenience and immediacy. However, ensuring that communication is accessible and easy to understand is just as important.

Many respondents reported difficulties with receiving NHS communication in their preferred format, leading to challenges in understanding medical information and difficulty navigating the healthcare system.

> We had the opportunity to be involved in the NHS Sussex Digital and Data Panel to ensure that accessibility and useability is considered at the development stage of any future communication strategies.
>
> An elderly man with age-related macular degeneration struggled to receive NHS communications in large print, leading to missed appointments and increased anxiety.

Access to NHS Services

Accessing healthcare independently poses serious challenge for many individuals, particularly due to mobility issues, confidence, barriers, and difficulties navigating healthcare facilities. The reliance on assistance for navigating appointments, checking-in, and understanding medical information highlights the need for more accessible healthcare environments.

- 68% of respondents felt they could not attend their medical appointments independently.

- 46% of respondents are unable to attend appointments independently stating mobility as one of the main contributing factors.

- 51% of respondents see navigating the environment as a barrier to independent attendance.

- 85% of respondents stated they require assistance getting to and from appointments. Support from family and friends being the most common form of transport assistance.

Assistance

73% of respondents who required further assistance after arriving for their appointment, had received this. The main reasons for requiring assistance were support to and from seats in the waiting area. Support to and from the appointment room. **5% of respondents** stated they needed support but did not receive any assistance, they also did not know what assistance was available nor how to access it. One respondent needed assistance checking-in for their appointment due to having dual sensory loss did not receive the support they required.

Appointments

14% of respondents felt the appointment duration was not sufficient to ask relevant questions and absorb the information being provided by the medical professional.

Inpatient Experiences

6% of respondents saw their sight condition as a barrier to accessing the appropriate care and support needed as an inpatient.

> Bright lights, signage, staff are unaware of differing lights and the effect on my vision. Bed position directly under lights, as this affects my balance. Staff asking me to look at something and the print screen was too small. Flooring looks all one big blur, with no markings to guide you.
>
> I had a spell in hospital in late 2022 after having a fall at home. I felt the staff, as lovely as they were, would often put things around my bed and say things like "it's on your left," or "lunch is on the table," I found this quite frustrating as had explained to numerous staff that I am blind, but it seemed to fall on deaf ears. However, regardless of this, the care I received was fantastic.
>
> I had to call an ambulance earlier, this year, due to abdominal pains. I should have a t-shirt with "I am blind." The nurses were telling me to "follow me", I did not know where I was meant to be following them too.

Impact on Health

The responses to the survey have shown some critical health challenges, particularly regarding visual impairment, mental health and multimorbidities. The main areas were access to care, long wait times, and difficulties navigating the system, which creates real barriers for individuals.

There is an urgent need for NHS services and other services to improve support services, enhance mental health services, and address transportation as this could make a huge difference in ensuring individuals receive the appropriate care they need and deserve.

Mental health

27% of respondents reported experiencing mental health issues. Many seeking support for anxiety, depression, and PTSD (Post-traumatic stress disorder). Often these issues went untreated (22%) due to barriers in accessing appropriate mental health services.

The main challenges in accessing mental health support are long waiting times, lack of available services, and difficulties in navigating the mental health care system.

> The lack of mental health support is really affecting my ability to manage my other medical conditions.

Co-Existing Conditions (multimorbidities)

Respondents living with visual impairment shared other health conditions they live with such as diabetes, heart problems, and hearing impairments. These multimorbidities compound the challenges individuals have managing their overall health and accessing appropriate care and support.

> A middle-aged woman with glaucoma and depression faced long waiting times for appointments, resulting in worsening mental health and vision.

Support and Services

There is a general lack of awareness about available support services for visually impaired and other disabilities. Many participants shared they do not know how to access services or have not been told about services by their healthcare providers.

There is a lack of awareness of how to access support services leading to individuals feeling isolated and frustrated. Only **40% of respondent**s have been referred or signposted onto appropriate support for their eye health conditions.

Support Received at diagnosis

Respondents reported varying levels of support from NHS services. 20% of respondents received assistance from Eye Clinic Liaison Officers (ECLOs) and Sight Care Advisors.

However, **57% of respondents** shared they are not aware if there was an ECLO/SCA in the eye clinic they attend.

Low Vision Services

Access to low vision services and aids is inconsistent, with some receiving helpful support and others struggling to access appropriate services. In certain areas of the county, there is no NHS funded Low Vision Service and in other areas there is a funded service. The eligibility criteria also varies for the service. This indicates a potential inequality and unequal access to service provision.

48% of participants were not aware of the Low Vision Service and only 43% have accessed the service at some point in the past.

Emotional and Practical Support

Participants expressed a need for more emotional and practical support, particularly at the point of diagnosis and discharge. The level of emotional and practical support at the point of diagnosis or discharge varied, with some feeling well-supported and others feeling neglected.

79% of respondents were not made aware of services and support available at the point of diagnosis. The lack of appropriate support led to feelings of isolation and frustration.

Discharge

33% of respondents discharged from the eye clinic were made aware of the importance of regular eye health checks. 32% of those who have been discharged, were not made aware of the ongoing support and services available to them after discharge.

> I feel like I'm constantly fighting to get the care I need. The communication barriers make it so difficult to understand what's going on with my health.

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Recommendations

Tackling these challenges requires a multi-faceted approach.

Strategies that could help improve access to appropriate support when living with visual impairment in Sussex:

Improved Communication:

Ensure that all NHS communication is available in accessible formats, such as audio, large print, Braille, and digital formats and are patient specific.

NHS accessibility and clarity in communication is ensured by adhering to the **Accessible Information Standard (AIS)** (now **Accessible Information Standard**) and the **NHS Identity Guidelines**.

The AIS requires NHS and adult social care providers to identify, record, and meet patients' information and communication needs, ensuring information is available in accessible formats (large print or British Sign Language) and communication support is provided. The NHS Identity Guidelines further mandate clear, concise, respectful, and professional communication, emphasising a direct and personal style for patient-facing materials to uphold patient values and improve health equity.

Mental Health Support:

The availability of early access -communication, information, and navigation -to mental health services and support, for individuals living with sight loss and other chronic conditions. Services for mental health need to be integrated with other healthcare services to enable the provision of a holistic service provision.

Accessibility:

The need to reduce waiting times for appointments to ensure that individuals receive timely access to healthcare services. It is also important to identify and address current inequalities for access to eye health services to ensure that all individuals receive equitable care.

Awareness of Support Services:

Increase awareness and availability of support services for visually impaired and other multimorbidities. Ensuring that all individuals are informed about available support services, including ECLOs, Sight Care Advisors, and low vision services. This will go a long way to providing consistent emotional and practical support at the point of diagnosis and discharge and support individuals to cope better with their conditions.

Sight Loss awareness training for NHS staff

What this lived experience project has shown is there is an urgent need for NHS staff to be aware of the difficulties faced by those who are living with a visual impairment. By having an increased awareness of the challenges faced, it is hoped that communication can be adapted to become more effective.

Individuals with visual impairments face numerous barriers in accessing healthcare, such as navigating buildings, using technology, and understanding non-verbal cues.

To provide accessible care, staff should follow the **NHS Accessible Information Standard**, offer information in large print, Braille, or audio formats, ensure clear signage, good lighting, and proactively ask individuals about their preferred communication methods.

Patient Journey Report

A patient Journey Report or Patient Passport could be an excellent way to notify to staff working with patients with sight conditions of their accessibility needs: preferred method of communications -written and verbal -as well as any other difficulties they may face.

Funding for VCSE partners to ensure patents can *Wait Well*

Appropriate funding and resources for support services so that individuals with disabilities, have access to the necessary tools and assistance.

Eye Care Support Pathway

It is recommended that the nationally endorsed **Eye Care Support Pathway** is embedded into NHS Sussex. As this will ensure that all patients receive full support and are able to wait well.
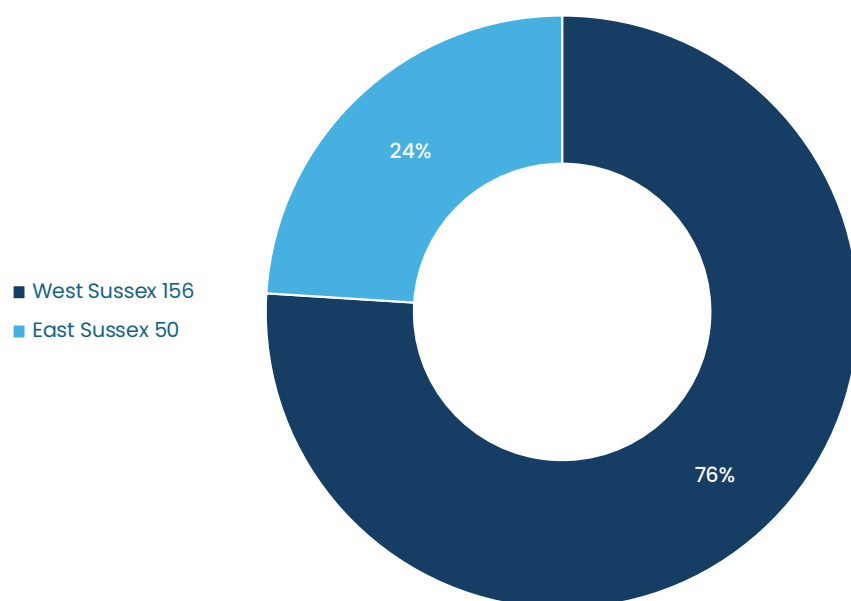
Integrated Health Services:

Combined care for [1]multiple health conditions, or **multimorbidity**, involves integrated, person-centred care models that coordinate treatments, focus on patient priorities, and aim to reduce fragmented and burdensome care.
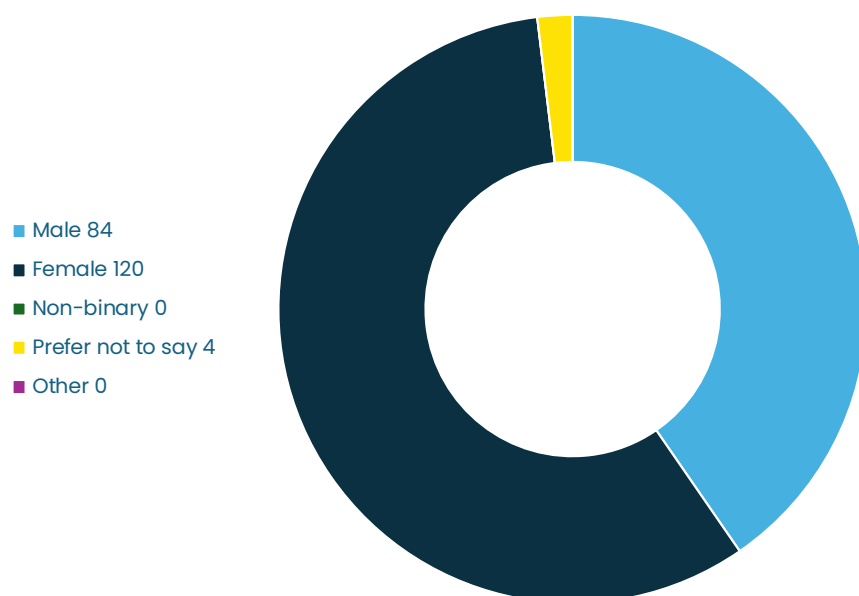
Appendix A

Demographics

216 people living with visual impairment were part of this project. 76% (n156) people live in West Sussex and 24% (n50) live in East Sussex.

- West Sussex 156
- East Sussex 50

24%

76%

Age of responders

- Male 84
- Female 120
- Non-binary 0
- Prefer not to say 4
- Other 0

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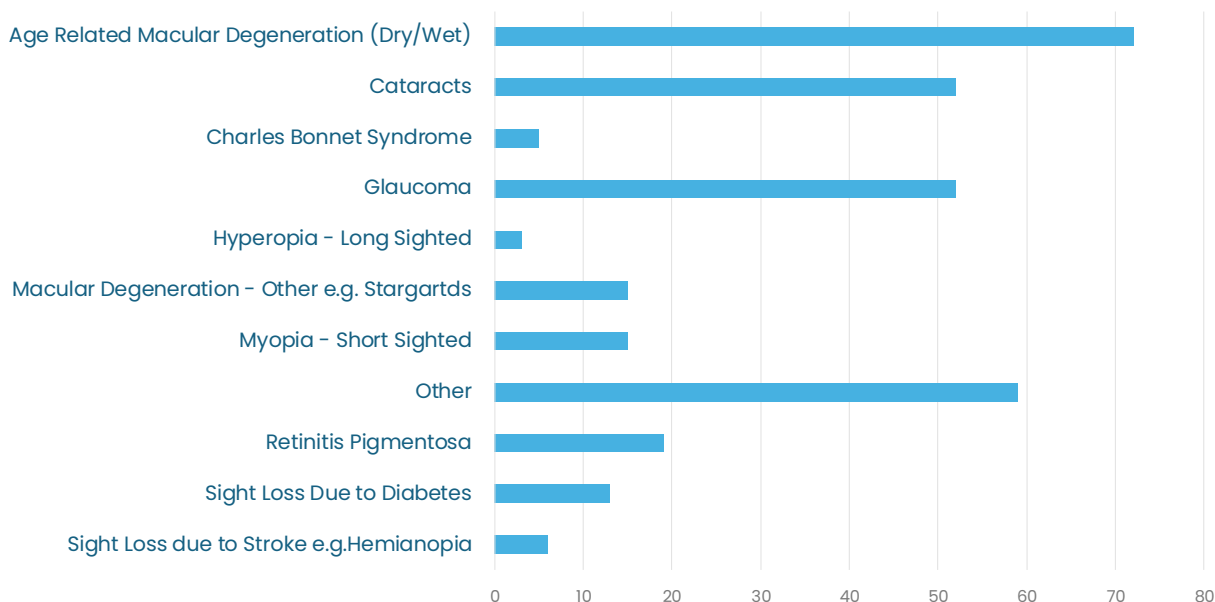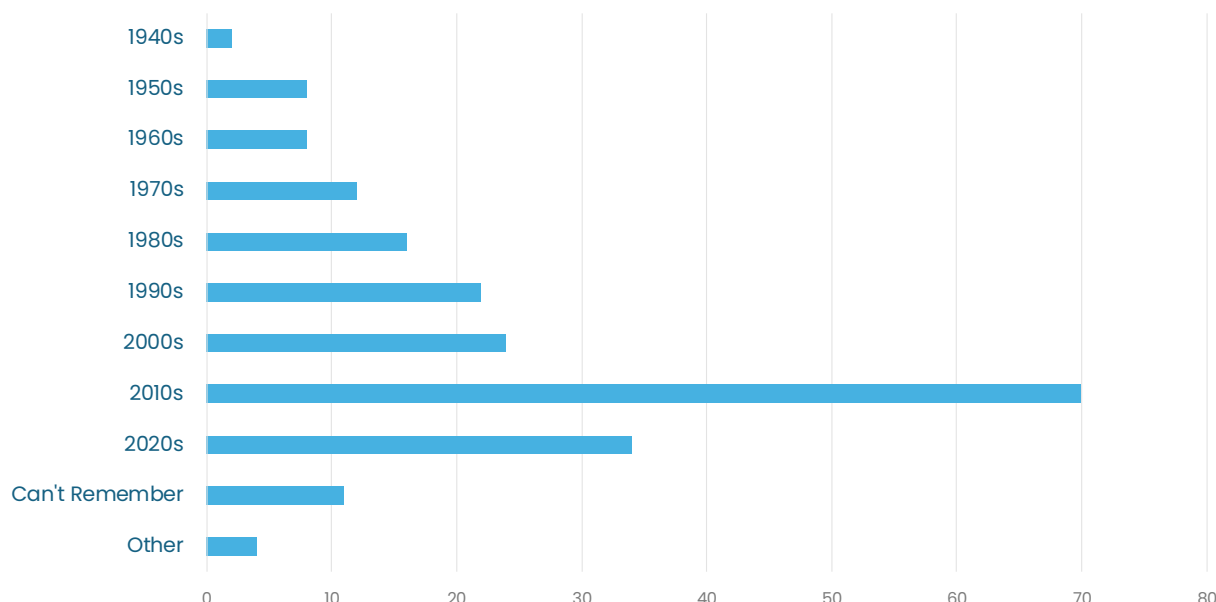
Diagnosed conditions

Wide range of diagnosed conditions were reported with 72 people living with Age Related Macular Degeneration (Dry/Wet), 59 people living with other eye conditions, 52 people living with Glaucoma, and 52 people living with cataract.

Condition	Value
Age Related Macular Degeneration (Dry/Wet)	~73
Cataracts	~51
Charles Bonnet Syndrome	~6
Glaucoma	~51
Hyperopia – Long Sighted	~4
Macular Degeneration – Other e.g. Stargartds	~14
Myopia – Short Sighted	~14
Other	~58
Retinitis Pigmentosa	~18
Sight Loss Due to Diabetes	~13
Sight Loss due to Stroke e.g.Hemianopia	~6

Diagnosis year

The year when primary eye condition was diagnosed shows that some responders have been living with sight loss for over 85 years. The majority were diagnosed in 2010.

Decade	Value
1940s	~2
1950s	~8
1960s	~8
1970s	~12
1980s	~16
1990s	~22
2000s	~24
2010s	~70
2020s	~34
Can't Remember	~11
Other	~4

Ethnicity

Most respondents were White British, (89%).

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4Sight Vision Support

An independent charity dedicated to supporting and engaging with people across West Sussex who are blind or partially sighted. Empowering people by providing tailored support, building confidence, and promoting inclusivity.

4Sight Vision Support is a caring and trusted team who will help relieve fear and anxiety by helping people to adapt and give them the confidence to do the things they want to do.

If you're supporting someone with sight loss, they're here for you too.

Services are available across West Sussex: anyone can contact us, you do not need to be referred.

Website: **4sight.org.uk**
Call: **01243 828 555**
Email: **enquiries@4sight.org.uk**

East Sussex Vision Support

East Sussex Vision Support aim is to increase the independence, confidence and well-being of blind and partially sighted people and also work to promote the understanding of sight loss and it's challenges in local communities, businesses, schools and organisations.

They also offer low vision support for workers, aids and equipment.

Website: **eastsussexvisionsupport.org**
Call: **01323 832252**
Email: **info@eastsussexvisionsupport.org**

Healthwatch West Sussex

Healthwatch West Sussex is proud to support 4Sight Vision Support in their endeavour to collect, review, and consolidate data, recognising the vital importance of amplifying the voices of people living with visual impairment and multimorbidity's.

We are pleased to have freely contributed our support in creating a summary of the report, helping ensure that lived experiences voices are at the heart of future improvements.

Website: **healthwatchwestsussex.co.uk**
Call: **0300 012 0122**
Email: **helpdesk@healthwatchwestsussex.co.uk**