

# Report of Engagement with People with Vision Impairment

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### **Acknowledgments**

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We would also like to thank all of the individuals who have contributed to this Report, and all of the organisations who have endorsed and supported this work. Our particular thanks go to Sight Concern Worcestershire, Macular Society and Worcestershire Sight Loss Council for their input to helping us understand the key themes and developing the recommendations contained in this Report.

## **EXECUTIVE SUMMARY**

### **ABOUT HEALTHWATCH WORCESTERSHIRE**

Healthwatch Worcestershire (HWW) gathers feedback about local publicly funded health and care services and makes recommendations to those who run them about how they could be improved from a patient, service user and carer perspective.

### **WHY THIS WORK**

Healthwatch Worcestershire has a long-standing interest in the experiences of adults living with significant vision impairment in Worcestershire. We recognise that whilst each person's experience of vision impairment is unique, this community of people may experience additional barriers when seeking to access and use health and social care services. Risk of vision impairment is heavily influenced by health inequalities.

The RNIB estimates that there are around 24,000 people living with significant vision impairment in Worcestershire. Of these, it is estimated that approximately 15,000 people meet the criteria to be registered as Sight Impaired (Partially Sighted) or Severely Sight Impaired (Blind) .

At 31<sup>st</sup> December 2023 there were 2111 people registered as Sight Impaired or Severely Sight Impaired in Worcestershire.

### **WHAT WE DID**

HWW held focused group discussions with 4 groups of people living with vision impairment in Worcestershire, engaging with 55 vision impaired people. We also worked with local organisations for Visually Impaired people to verify the key themes that emerged from these discussions, and to develop the recommendations that we have set out in this Report. The organisations are Sight Concern Worcestershire; Macular Society and Worcestershire Sight Loss Council. We gathered this information between October 2023 and February 2024.

We spoke with more women than men. We are conscious that we have largely engaged with those people who are connected to existing services.

### **WHAT WE FOUND OUT**

#### **Diagnosis, Certification and Registration**

We heard of mixed experiences of receiving a diagnosis and prognosis of a vision impairment from ophthalmologists, and of the type of support people subsequently received. Positive examples were greatly appreciated, but were not consistently echoed by others. We were informed of an apparent lack of sensitivity when the diagnosis of vision impairment had been explained. Some reported they were not directed to, or given any appropriate information about what would happen next. The role of support organisations was not always clearly explained.

For some people, we were told that registering as sight impaired or severely sight impaired with Social Services had been straightforward, positive and helpful. Others stated that they had not been aware of the registration process, or found it a difficult process to understand and navigate. Some people reported they were not aware of being registered at all, and could not recall being contacted by anyone from Social

Services. People with vision impairment who are eligible to be registered may be missing out on some key benefits that registration can bring.

### **Eye Clinic Liaison Officer (ECLO) Role**

The organisations that we spoke with identified a gap in service provision in Worcestershire in that we are the only Integrated Care Board in the West Midlands that does not have an ECLO role in hospital settings. The lack of the ECLO co-ordinating role has led to some people feeling unsupported at the potentially distressing time of diagnosis and Certification. Individuals and organisations we consulted expressed support for ECLO workers to be made available to eye clinics in Worcestershire where a diagnosis may be made.

### **Access to Health Services**

Some individuals described the difficulties they experienced trying to book follow up appointments which had been advised by an ophthalmologist. They faced barriers in getting through to the appropriate person and then facing wait times for an appointment. Cancellation of appointments, often without adequate or accessible notice was another issue that people had experienced. We were also told by several individuals and local organisations that there is no 'Out of Hours' access to hospital ophthalmology services in Worcestershire, and that patients must use relevant services in Birmingham.

### **Support to Adapt to Day to Day Life**

We were informed about significant variation in the support that people had received to enable them to adapt to day to day life. This included access to mobility and orientation training, daily living skills and other learning opportunities. Not everyone at the Groups we consulted had heard of, or were aware of the role of the Worcestershire County Council Sensory Impairment Team. It appeared that there was sometimes confusion about the role of different agencies, the services they provide and which agency the individual had been in contact with.

### **Awareness about Vision Impairment amongst Health and Care Service Staff**

We heard some reports of good practice by staff who went the "extra mile" to support Vision Impaired people. Conversely, we heard about a lack of awareness about interacting with those with vision impairment. Examples identified included lack of verbal communication, inaccessible instructions and information, lack of knowledge about how to guide a person with a vision impairment and perspex screens which make it more difficult for some vision impaired people to see and hear what is being said. Many people said that the lack of awareness by staff had led to considerable difficulties for them, which could be improved by appropriate vision awareness training.

### **Information and Advice Required by Vision Impaired People**

We were told by the majority of those consulted that inaccessible information was a major problem for them. Appointments, information and advice about NHS and Social Care services is often very difficult to read. Printed information has generally been the principal format provided by NHS and Social Care, in many different font sizes, types, colours and formatting systems. Printed material is gradually being superseded by online information, and similar issues of inaccessibility are arising

due to websites which are not yet fully accessible or user friendly for those with vision impairments. In addition, not everyone is able to use computers, smart phones and the internet. Furthermore, some people informed us they did not have the facilities to access digital information, nor wanted to access digital services. It is worth remembering that many of those who are registerable as sight impaired are older adults who may have little or no experience of using 'smart technology'.

For those who do go online, websites need to be designed so that they are fully accessible, and user-friendly for Visually Impaired people using assistive software. There was also a lack of awareness, amongst those consulted, about the 'Accessible Information Standard' (AIS). People's experience of how the AIS worked in practice also varied widely.

## **CONCLUSION**

Many of the issues raised by people with a vision impairment and documented in this Report are not new. It is likely that our findings are already familiar to those living with vision impairment, as well as to those working in social care and health systems delivering services and support to people living with vision impairment.

This should add a sense of urgency to address the issues that have been raised through this Report. Those people living with vision impairment that we listened to often felt left out and let down by service providers, and felt frustrated by, and resigned to a perceived lack of progress to improve access and accessibility to health and care services. We look forward to the system response.

## **RECOMMENDATIONS**

1. Identify system wide governance and clear leadership at Integrated Care Board level which takes responsibility for health and care services for people living with Vision Impairment
2. Ensure that services meet the requirements of the Accessible Information Standard. This includes a legal requirement to ask people about their communication needs, record and flag this information on records, pass it on to others when appropriate and ensure that the need is met.
3. Ensure that health and social care information is available in a variety of formats as appropriate to people's individual needs. This should include paper, digital and braille formats.
4. Consider the introduction of the Eye Clinic Liaison Officer (ECLLO) role within Worcestershire in every secondary health setting where a diagnosis may be made.
5. If resources are not available to fully implement the ECLLO role ensure that responsibility for ECLLO functions as described by the RNIB are allocated to appropriate clinic staff, so that people get the support they need at diagnosis
6. Consider how people can be provided at the point of diagnosis with access to appropriate information, signposting and advice available in a variety of formats
7. Review processes to ensure that Registration as Sight Impaired is streamlined, and consistently responsive from the perspective of service users

8. Ensure that there is sufficient capacity within the Worcestershire County Council Sensory Impairment Team to meet the requirements of users, and potential users, of the service
9. Consider the provision of vision impairment awareness training for front line staff in health and social care

## 1. ABOUT HEALTHWATCH WORCESTERSHIRE

Healthwatch Worcestershire (HWW) gathers feedback about local publicly funded health and care services and makes recommendations to those who run them about how they could be improved from a patient, service user and carer perspective.

## 2. WHY THIS WORK

Healthwatch Worcestershire has a long-standing interest in the experiences of adults living with significant vision impairment in Worcestershire.

We recognise that whilst each person's experience of vision impairment is unique, this community of people may experience additional barriers when seeking to access and use health and social care services.

Risk of vision impairment is heavily influenced by health inequalities, including health and disabling conditions, ethnicity, socioeconomic deprivation and ageing. Vision impairment can also increase the risk of depression, falls and hip fractures, loss of independence, social isolation and living in poverty.<sup>1</sup>

Research suggests that people with a vision impairment can feel cut off and isolated from other people and things around them. This is often exacerbated by: difficulty with managing everyday tasks; problems navigating built environments / pavements; using public transport; inaccessible forms of information; actual or inadvertent forms of discrimination; and, lack of awareness of, and stereotypical attitudes about sight loss and vision impairment.<sup>2</sup>

According to the RNIB, by 2050, the numbers of people living with significant vision impairment, in the UK, are projected to increase to over four million.<sup>3</sup> This is based on the assumption that the underlying risk factors associated with vision impairment do not change and that broad demographic changes, such as an aging population and increasing rates of diabetes will continue in coming decades<sup>4</sup>.

It is therefore particularly important that the needs of people living with vision impairment in Worcestershire are understood, recognised and addressed without further delay.

## 3. PEOPLE LIVING WITH VISION IMPAIRMENT IN WORCESTERSHIRE

### Numbers of people with vision impairment in Worcestershire

The RNIB estimates that there are around 24,000 people living with significant vision impairment in Worcestershire. Of these, it is estimated that approximately 15,000 people meet the criteria to be registered as Sight Impaired (Partially Sighted) or Severely Sight Impaired (Blind)<sup>5</sup>. For more information about Registration please see below.

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<sup>1</sup> Sight loss: a public health priority (2014), RNIB <http://www.rnib.org.uk/services-we-offer-advice-professionals-health-professionals/public-health-professionals>

<sup>2</sup> Connect Voices Tracker survey, series of reports. Part of Voice of the Customer series. RNIB.

<sup>3</sup> Pezzullo L, Streatfield J, Simkiss P, and Shickle D (2018) The economic impact of sight loss and blindness in the UK adult population. BMC Health Services Research, 18:63; Deloitte Access Economics (2019) The economic impact of sight loss and blindness in the UK adult population. RNIB and Office for National Statistics (2015) 2014-based National Population Projections: Principle projections.

<sup>4</sup> Government Office for Science (2016) Future of an Aging Population. HM Government.

<sup>5</sup> Based on RNIB key statistics about sight loss in the UK. [Learn more about sight loss statistics across the UK | RNIB](#)

Figures supplied by Worcestershire County Council show that, at 31<sup>st</sup> December 2023, there were 2,111 people who are registered as Sight Impaired or Severely Sight Impaired in Worcestershire.

Of these 1016 are registered as Blind/Severely Sight Impaired and 1095 are registered as Partial Sight/Sight Impaired.

The table below shows the breakdown by District

District	Blind/ Severely Sight Impaired	Partial Sight / Sight Impaired	Total
Wyre Forest	177	192	369
Worcester	171	191	362
Wychavon	155	205	360
Bromsgrove	164	164	328
Malvern Hills	154	172	326
Redditch	136	120	256
Out of County	59	51	110
<b>Total</b>	<b>1016</b>	<b>1095</b>	<b>2111</b>

A possible reason for the difference between the numbers of people registered, and the numbers of people who may be eligible for registration is the likelihood that some older adults will accept declining vision as an inevitable consequence of ageing without seeking medical help or treatment.

Significantly more women than men experience vision impairment, possibly due to gender differentials in longevity. Nationally, it is estimated that 61% of people living with Vision impairment are women.<sup>6</sup>

In Worcestershire there are more women than men on the Register.

Gender	Blind/ Severely Sight Impaired	Partial Sight / Sight Impaired	Total
Female	578	660	1238
Male	438	435	873
<b>Total</b>	<b>1016</b>	<b>1095</b>	<b>2111</b>

Most of those registered, 1,570 people, are aged 65+, with a further 541 people aged between 18-64.

No. of people	Vision impairment		
Age band	Blind/ Severely Sight Impaired	Partial Sight / Sight Impaired	Total
<b>Age 18-64</b>	<b>296</b>	<b>245</b>	<b>541</b>
18-49	148	123	271
50-64	148	122	270
<b>Age 65+</b>	<b>720</b>	<b>850</b>	<b>1570</b>
65-74	117	103	220
Age 75+	603	747	1350
<b>Grand Total</b>	<b>1016</b>	<b>1095</b>	<b>2111</b>

<sup>6</sup> RNIB ibid



It is generally acknowledged that approximately two thirds of those experiencing significant vision impairment are older adults, aged above 65 years, who experience age-related eye conditions<sup>7</sup>.

The most common cause of vision impairment in older people nationally is ageing maculopathy (Age Related Macular Degeneration)<sup>8</sup>.

For those of working age the most common cause nationally is diabetic retinopathy (diabetic related vision impairment).<sup>9</sup>

People with vision impairment have a significantly lower employment rate compared to the UK general population average. It is reported that only one in four people of working age who are registered with a vision impairment are in employment.<sup>10</sup>

### **Registering as Sight Impaired or Severely Sight Impaired**

Worcestershire County Council has a legal duty to maintain a register of people who are sight impaired or severely sight impaired living in the County.

When consultant ophthalmologists decide a person's sight meets the requirement for certification, either as sight impaired or severely sight impaired, they may issue a certificate of visual impairment (CVI). A copy of the CVI should then be sent to the individual concerned, and to the Worcestershire County Council Sensory Impairment Team. A specialist worker from the Sensory Impairment Team should then contact that person to discuss the option of being added to the register. The Sensory Impairment Team worker should also offer to provide an assessment of needs, other relevant advice, and the provision of specific services to meet any identified needs.

Other benefits of registration may include easier access to concessions such as Blue Badge parking scheme, half-price TV Licence, help with NHS costs, help with Council Tax bill and tax allowances, leisure discounts and free public transport. The concessions people may be entitled to may depend upon whether they are registered as severely sight impaired or sight impaired. Registration does not automatically entitle anyone to specific welfare benefits, but it may help as evidence if benefits are claimed. Those who are registered are issued with a registration card that proves their registration status as a vision impaired person.

It is important to note that, not everyone will meet the requirements for Certification, and even if they do individuals may choose not to be added to the local authority register.

### **The Care Act 2014**

In England, local authorities have a legal obligation under the Care Act 2014 to help people with vision impairment to develop practical skills and strategies to maintain independence, including:

- at least 6 weeks of free vision rehabilitation

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<sup>7</sup> RNIB key statistics about sight loss in the UK. [Learn more about sight loss statistics across the UK | RNIB](#)

<sup>8</sup> RNIB *ibid*

<sup>9</sup> RNIB *ibid*

<sup>10</sup> Slade (2019) Understanding Society: comparing the circumstances of people with sight loss to the UK population. RNIB.

- free community equipment, including minor adaptations to the home where this costs £1000 or less.

In Worcestershire this service is provided through Worcestershire County Council Sensory Impairment Team, who are part of the Adult Social Care Service.

#### **4. WHAT WE DID**

HWW held focused group discussions with 4 groups of people living with vision impairment in Worcestershire, engaging with 55 vision impaired people. Three of these groups were Sight Concern Connections groups held in Worcester, Kidderminster and Bromsgrove. We attended the Macular Society Group held in Malvern.

We also met with the Worcestershire Sight Loss Council to discuss the experience of Council members.

Some common themes emerged from the discussions we held. These themes reflect previous engagements we carried out with vision impaired people, which were paused due to Covid-19 restrictions.

We also worked with the following organisations for vision impaired people in order to verify the key themes and also to develop the recommendations that we have set out in this Report.

- Sight Concern Worcestershire
- The Macular Society
- Worcestershire Sight Loss Council

Their contribution has been invaluable, and has added further lived experience of people living with vision impairment in Worcestershire to the voices that we heard during our engagement activities.

We are conscious that we have largely engaged with those people who are connected to existing services. We cannot be sure that their experience is similar to people who are living in the community who are not involved with representative groups and organisations. Nevertheless the themes that have emerged illustrate some of the challenges faced by people living with vision impairment in Worcestershire.

#### **5. DIAGNOSIS, CERTIFICATION AND REGISTRATION**

##### **Diagnosis**

We heard of mixed experiences of receiving a diagnosis and prognosis of a vision impairment by ophthalmologists, and of the type of support people subsequently received. For example, some individuals told us they had been given good, appropriate and clear information about their diagnosis and prognosis, the available treatment options, and the potential support and equipment that may be available. Such positive examples were greatly appreciated, but were not consistently echoed by others.

We were informed of a number of experiences relating to an apparent lack of sensitivity when the diagnosis of vision impairment had been explained. Some individuals reported being given an upsetting diagnosis with no time to regain their composure before being told that no more treatment was available. One person recalled being told that she was being “Registered” as severely sight impaired, and that she should not drive again. She said she was helped, in tears, out of the room in a distressed state, and not knowing what to do as her car was in the hospital car park.

Across the Groups we consulted, others described being told they would eventually lose their sight, that no further treatment was available for their condition, and being “signed off” without further support or information. Some reported they were not directed to, or given any appropriate information about what would happen next.

The Council’s Sensory Impairment Team told us that they provided information in Ophthalmology Departments to be shared with people, but often only receive referrals when the Certificate of Vision Impairment is issued rather than as part of routine communication/information given to people following diagnosis.

Additionally, at times, the role of support organisations was not clearly explained. For example one person reported they were referred to Sight Concern to attend a low vision clinic. The person wrongly expected to meet a consultant at the appointment, and be offered a treatment programme.

It was commonly felt that being given the diagnosis of permanent sight loss was life changing, and its impact was often distressing. It was also felt that the diagnosis should be delivered with sensitivity and compassion.

One participant described speaking with a Sight Concern volunteer following diagnosis, and continued by saying how supportive and reassuring it was. The majority of individuals said they did not have access to this type of support after diagnosis. Many individuals stressed the provision of additional, alternative support in ophthalmic clinics would be greatly appreciated, and should be seriously considered.

### **Certification and Registration**

It is the clinical judgement made by an ophthalmologist to certify people either as Sight Impaired (partially sighted) or Severely Sight Impaired (blind) depending upon their type and degree of vision impairment. The certificate is then forwarded to the local authority Social Services Department for possible registration. It is the Local Authority who keep the Register. Not everyone will meet the requirements for certification and therefore registration.

For some people, we were told that registering as sight impaired or severely sight impaired with Social Services had been straightforward, positive and helpful. Several individuals said they were issued with a Certificate of Visual Impairment via an ophthalmologist, and the Sensory Impairment Team followed this up to complete the registration process, offer an assessment and appropriate services.

Others stated that they had not been aware of the registration process, or found it a difficult process to understand and navigate. Some people reported they were not aware of being registered at all, and could not recall being contacted by anyone from

Social Services. One person, for example, reported having been provided with a copy Certificate from an ophthalmologist, but this was not followed up by a contact from the County Council Sensory Impairment Team. Such comments may be isolated examples or could indicate a lack of consistency in the protocol of contacting and communicating with newly referred individuals to the Sensory Impairment Team.

The figures estimated by the RNIB indicate a large discrepancy between the numbers of people estimated to be eligible for registration and those that are actually registered. People with vision impairment who are eligible to be registered may be missing out on some key benefits that registration can bring.

## **6. EYE CLINIC LIAISON OFFICER (ECLO) ROLE**

The organisations that we spoke with identified a gap in service provision in Worcestershire compared with other local authority areas in the West Midlands. We were informed that across the West Midlands Herefordshire & Worcestershire is the only Integrated Care Board that does not have an Eye Clinic Liaison Officer (ECLO) role in hospital settings.

The RNIB describes the ECLO role as follows:

“ECLOs act as an important bridge between health services and social services, and are central to the support and wellbeing of patients in eye clinics. They also help prevent avoidable sight loss, by talking through treatment and helping people to understand their medication if necessary... ECLOs are there to provide .. up-to-date information and put you in touch with useful services by making referrals on your behalf.”

The lack of the ECLO co-ordinating role has led to some people feeling unsupported at the potentially distressing time of diagnosis and Certification. In other areas where ECLO workers are available, patients report having the opportunity and time to discuss the diagnosis, and being provided with relevant, accessible information, opportunities for further support, training and benefits<sup>11</sup>

Individuals and organisations we consulted expressed support for ECLO workers to be made available to eye clinics in Worcestershire where a diagnosis may be made.

*Quote from participant: “You need to know that yes, you may go blind, but there’s help, there’s hope”*

## **7. ACCESS TO HEALTH SERVICES**

Ophthalmology services were frequently discussed by those consulted due to the importance of this service for them. Certification apart, some individuals described the difficulties they experienced trying to book follow up appointments which had been advised by an ophthalmologist. They faced barriers when trying to do so in getting through to the appropriate person and then facing wait times for an appointment.

Another individual described attending three separate appointments to have a prosthetic eye cleaned, and on each occasion the appointment had been cancelled

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<sup>11</sup> [Eye Clinic Liaison Officer \(ECLO\) service UK Evaluation Report \(rnib.org.uk\)](https://www.rnib.org.uk)

without their knowledge. These cancellations reportedly led to a 5 month delay in the eye being cleaned.

Another person had the frequency of their eye injections changed as a result of a change to a treatment programme, the individual concerned said that this had not been explained clearly and they were left anxious about the change.

We were also told about changes to, or cancellations of appointments without adequate or accessible notice. These examples highlight the importance of appropriate notice and accessibility of information. These issues will be covered in more detail later.

We were also told by several individuals and local organisations that there is no 'Out of Hours' access to hospital ophthalmology services in Worcestershire, and that patients must use relevant services in Birmingham. Whilst this aspect of service delivery may be currently unavoidable, it reinforces the importance of ensuring consistently accessible, empathic and reliable routine and scheduled services to be available at all other times.

## **8. SUPPORT TO ADAPT TO DAY TO DAY LIFE**

We were informed about significant variation in the support that people had received to enable them to adapt to day to day life. This included access to mobility training, daily living skills and other learning opportunities. Not everyone at the Groups we consulted had heard of, or were aware of the Worcestershire County Council Sensory Impairment Team.

People who had received rehabilitation services from the Sensory Impairment Team said that they were provided with valuable advice, equipment, support and ways of managing daily living.

Some stated however that they felt discouraged by staff from undergoing a full Care Act Needs Assessment, as they were likely to have to pay for any resulting care. That is, they were likely to be a "self-funder". Seemingly, it was suggested to them that, under these circumstances, there was not much point in having an assessment, as they would not be offered support from the County Council. It is worth noting that a Care Act needs assessment should be available to everyone, regardless of their financial circumstances.

Furthermore, we were told that a person who qualified for Social Care support had learnt about Personal Budgets from a friend after involvement with Social Services, and not from Social Services directly. This individual believed that a Personal Budget had the potential to be personally transformative, but this option had not been mentioned and offered.

Through our engagement it became clear that there was sometimes confusion about the role of different agencies, the services they provide and which agency the individual had been in contact with.

Whilst these examples may be the exception it is crucial that there is sufficient, timely access to comprehensive rehabilitation services to enable people to develop new skills, rebuild confidence and maintain independence. Younger adults we spoke with said they would have welcomed more mobility training to enable them to travel

more widely and safely around frequently used routes, and around diverse settings in their local area.

Access to training in communication skills, such as braille and other reading techniques using low vision aids, may be available in some cases. It was claimed by others that such training opportunities were not always available in sufficient intensity or frequency, or delivered by preferred methods.

It was recognised by most people that local not-for-profit organisations are trying to provide a wide range of complementary services and support to meet the needs of individuals. It was felt that lack of funding and capacity to do so as comprehensively as they would wish contributes to a shortfall in training opportunities.

### **Online services**

Many individuals informed us that utilising online and digital means of service delivery presented particular challenges for them.

Whilst some welcomed the opportunity to use online methods to access health care services, others found it difficult or impossible. Examples provided included the requirement to complete online forms for triage prior to getting a GP appointment. Whilst this requirement can be completed by a GP receptionist over the phone some felt that this added delay and difficulty in accessing their GP. Others reported that, whilst they were comfortable with telephone conversations with GP's and health professionals, they found video calls challenging. Some stated they were asked to send a photograph of bodily areas of concern, to a GP, and that this was very difficult for some, and impossible for others. Such requests are particularly difficult as they could not see sufficiently well to either photograph their problem condition, or focus their smartphone on the affected area.

As more and more services become mainly available online, it is important that they are designed to optimise accessibility and ease of use. Furthermore, for those who are unable to use online services, accessible, clearly available alternatives are provided .

## **9. AWARENESS ABOUT VISION IMPAIRMENT AMONGST HEALTH AND CARE SERVICE STAFF**

We heard some reports of good practice by staff who went the “extra mile” to support vision impaired people. For example, it was reported that reception staff, nurses and doctors called for people by name, and guided individuals to consulting and treatment rooms. Such assistance was greatly appreciated and welcome.

Conversely, we heard about a lack of awareness about interacting with those with vision impairment. Many people said that the lack of awareness by social care and NHS staff had led to considerable difficulties for them.

Examples given included:

- Appointments and information being provided in inaccessible printed formats. Some people reported that this had caused them to miss their appointments.
- Not being informed, in an inaccessible format, that their appointment had been cancelled and / or changed. This led to some attending for appointments that were no longer available, sometimes incurring substantial financial costs.

- Difficulties “signing in” on digital screens in GP waiting areas.
- Unclear or inaccessible and non-standard signage in hospitals and other health care settings.
- On asking for directions in healthcare settings, being given unhelpful directions such as: “It’s over there”, or “It’s down the corridor, third door on the right”, or to “Look for the red door.”. One individual, carrying a white cane, was told to: “Follow the red line on the floor”. Clearly, such directions are of little use to people with a vision impairment.
- Being unable to see, or read screens which provide information.
- Reception staff failing to verbally inform people that it is their turn to see a health professional, or announcing names too quietly in busy, noisy waiting areas.
- Patients having their name called clearly in the waiting area, which was very helpful, but guiding was not offered to the appointment / treatment area.
- Staff in hospital departments (including ophthalmology) not knowing how to guide people with a vision impairment.
- Receiving printed letters, information leaflets or instructions that are not accessible, including about prescribed medication
- Perspex screens which make it more difficult for some vision impaired people to see and hear what is being said.
- Lack of explanation for a hospital inpatient about the written daily food menu, even though the white board above the persons bed indicated they were visually impaired.
- Lack of awareness of transport issues for visually impaired people, who may be unable to drive or safely use public transport to attend medical appointments which are located a long way from where they live

Clearly, a number of issues in this respect crossover, or overlap with, Accessible Information Standards, and could be improved by appropriate vision awareness training.

*Quote from participant: “I spent £72 on cabs to Redditch and back, and when I got there my appointment had been cancelled”*

## **10. INFORMATION AND ADVICE REQUIRED BY VISION IMPAIRED PEOPLE**

We were told by the majority of those consulted that inaccessible information was a major problem for them. Appointments, information and advice about NHS and Social Care services is often very difficult to read. Printed information has generally been the principal format provided by NHS and Social Care, in many different font sizes, types, colours and formatting systems. Printed material is gradually being superseded by online information, and similar issues of inaccessibility are arising due to websites which are not yet fully accessible or user friendly for those with vision impairments. In addition, not everyone is able to use computers, smart phones and the internet. Furthermore, some people informed us they did not have the facilities to access digital information, nor wanted to access digital services. It is worth remembering that many of those who are registerable as sight impaired are older adults who may have little or no experience of using ‘smart technology’.

For those who do go online, websites need to be designed so that they are fully accessible, and user-friendly for sight impaired people using assistive software. There was also a lack of awareness, amongst those consulted, about the ‘Accessible

Information Standard' (AIS). People's experience of how the AIS worked in practice varied widely from some knowledge to no knowledge at all.

About half of the people we engaged with said they went online to look for information and advice. Equipment used included laptops, tablets / iPads and smartphones. Most of these said they were comfortable with finding information on the web. Others said they went online only because they had little choice, and they sometimes struggled to know where to look for trusted information sources.

Not all websites work well for people who are visually impaired and use screen readers. It is particularly important that those websites relating to health and social care services are fully accessible. Healthwatch Worcestershire carried out a Mystery Shopping exercise in March 2023 looking at the accessibility of information on Worcestershire County Council's website about Adult Social Care. At that time there were significant issues relating to accessibility and ease of use for vision impaired people wishing to access these webpages. Since then the Council has told us that in response to our Report:

"The accessibility of our website has been a primary focus. We have invited users of assistive technology to come and demonstrate the barriers they were experiencing as well as sought help from Government Digital Service who are our monitoring body to help us address the accessibility issues highlighted. Our website provider is now well versed in screen reader testing and have developed new skills in using NVDA. The council also commissioned a live audit of the website, which was tested with a screen reader and keyboard only. Speakeasy now are actively working with us around our online services and information.

The site has seen some major changes due to this, such as; the inaccessible navigation menu has been removed, breadcrumb navigation has been added and labels are now coded to announce to screen readers amongst other things. This is an ongoing commitment to ensure that what we develop moving forward gets checked and tested by both our web team and website provider."

For those who were unable to use the internet, or who had great difficulty using it, we were told that finding relevant information and advice independently could be a real struggle. Given some of the broader physical, emotional and mental health challenges facing people experiencing vision impairment, we asked specifically about awareness of public health messaging relating to Worcestershire Health Walks and Woo (a text based mental health support service). Only 6 people reported hearing of Health Walks, and no one reported hearing of Woo. When asked where people would look for health information, a range of sources were identified, including: television, libraries, group meetings, and word of mouth.

GP surgeries can be a trusted source of information and advice. Many respondents we consulted said they could no longer go into their GP surgery, and if they did, they could not always read the information on the notice boards. There was a general feeling amongst everyone that people with impaired vision often "missed out" on important and useful information and advice that is available to those with good sight.

In this respect, the dependence on others to access information also raises concerns about privacy and confidentiality. Some individuals feel that staff may assume that



family members or friends will read inaccessible information to vision impaired patients.

At the time of writing this report, we are aware that Worcestershire County Council have commissioned Sight Concern to provide information and advice services targeted at people with sensory impairments. It is hoped that the Sensory Matters service will significantly and consistently improve access to information, and signposting to sources of advice and support for people living with a sensory impairment.

It should also be remembered that people with vision impairments also require accessible information and advice about all other aspects of health and social services provision, and not just those about sensory impairment. For example, one individual reported attending a cancer clinic, and being provided with a substantial amount of printed material that they could not read. The same information in an accessible format was requested by the patient, but this is seemingly unavailable. A vision impaired parent also reported requesting accessible information regarding medical issues for their children, and this was also unavailable.

The Accessible Information Standard (AIS) 2017 is a mandatory standard that the NHS and social care services must follow. The aim is that people receive information in an accessible way, and they have the communication support they need. The Standard requires that people are asked if they have any communication needs, and if so, how these needs can be met. Identified needs should then be recorded and flagged, so as to prompt consistent action to meet them. This information should be shared with other NHS and social care providers.

Not everyone in the Groups had heard of the Accessible Information Standard. Some people did describe good practice at their GP surgery or at hospital appointments. Their communication needs had been discussed and staff worked to meet them. One individual, with assistive technology, said they asked a Medical Secretary for an appointment letter and accompanying information as email attachments, and these were provided.

Many others, however, did not recall being asked about their communication needs. Many people described commonly receiving printed information which was not accessible to them, text messages that they were unable to read, and being told to complete an online form which they were unable to access and complete independently.

We were told that appointment letters for the Ophthalmology Department use small print on white paper, which many people found difficult to read. It was stated that larger print letters on yellow paper would be easier for some vision impaired individuals to read. We were also informed that commissioned eye services used text messaging to ask people to make online appointment bookings or to confirm or inform people of appointments. This was reported to be helpful for some, but not for all.

Other work done by Healthwatch Worcestershire has suggested that the implementation of the AIS varies considerably across NHS and Care services in the County. Consistent implementation of the AIS is key to ensuring that people's communication needs are understood, noted and met.

*Quote from participant: "You're not provided with information, if you're lucky you have someone fighting alongside you for information, or if not you're just left ... so we miss out"*

## **11. CONCLUSIONS**

Many of the issues raised by people with a vision impairment and documented in this Report are not new.

It is likely that our findings and the key themes that we have identified are already familiar to those living with sight impairment, as well as to those working in social care and health systems delivering services and support to people living with vision impairment.

This should add a sense of urgency to address the issues that have been raised through this Report.

People told us of a lack of accessible information for vision impaired people and a lack of accessible formats for vision impaired people to provide information to service providers. We were told of mixed experiences of receiving a diagnosis, with some people feeling that this lacked sensitivity. Information, signposting and support provided post diagnosis was patchy, perhaps reflecting the lack of an Eye Clinic Liaison Officer role. The registration process was not always seamless. Support for people to adapt to their day to day lives was welcomed but perceived as limited by some. We were told that, at times, service providers lacked awareness, knowledge and understanding about the impact of vision impairment.

Those people living with vision impairment that we listened to often felt left out and let down by service providers, and felt frustrated by, and resigned to a perceived lack of progress to improve access and accessibility to health and care services.

This Report contains a series of recommendations which have been developed and endorsed through dialogue with the following organisations:

- Sight Concern Worcestershire
- Macular Society
- Worcestershire Sight Loss Council

We jointly believe that implementation of these recommendations will improve the health and care experience of people living with Vision impairment living in Worcestershire. We look forward to the system response.

## **12. RECOMMENDATIONS**

1. Identify system wide governance and clear leadership at Integrated Care Board level which takes responsibility for health and care services for people living with Vision Impairment
2. Ensure that services meet the requirements of the Accessible Information Standard. This includes a legal requirement to ask people about their communication needs, record and flag this information on records, pass it on to others when appropriate and ensure that the need is met.

3. Ensure that health and social care information is available in a variety of formats as appropriate to people's individual needs. This should include paper, digital and braille and audio formats.
4. Consider the introduction of the Eye Clinic Liaison Officer (ECLO) role within Worcestershire in every secondary health setting where a diagnosis may be made.
5. If resources are not available to fully implement the ECLO role ensure that responsibility for ECLO functions as described by the RNIB are allocated to appropriate clinic staff, so that people get the support they need at diagnosis
6. Consider how people can be provided at the point of diagnosis with access to appropriate information, signposting and advice available in a variety of formats
7. Review processes to ensure that Registration as Sight Impaired is streamlined, and consistently responsive from the perspective of service users
8. Ensure that there is sufficient capacity within the Worcestershire County Council Sensory Impairment Team to meet the requirements of users, and potential users, of the service
9. Consider the provision of vision impairment awareness training for front line staff in health and social care

We look forward to the system response.

### **13. ENDORSEMENTS**

This Report and its recommendations have been endorsed by the following organisations.



## **Worcestershire Sight Loss Council**