

# **Eye Clinic Observations Southlands and St. Richard's Hospitals Eye Clinics**



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# Executive Summary

This report is the result of a partnership between 4Sight Vision Support, Healthwatch West Sussex and the University of Chichester.

The aim of the study was to identify patient experience and service knowledge of people who accessed the eye clinics at Western Sussex Hospitals NHS Foundation Trust (WSHFT) Southlands and St. Richard's hospitals.

A total of 85 people voluntarily participated in the study, with interviews taking place between 12 July and 17 August 2018.

The study has shown an overall positive patient experience at both Eye Clinic's, however, patient feedback highlights issues around:

- difficulties with the appointments process
- length of waiting times whilst in clinics
- poor communication between healthcare professionals and patients - particularly in relation to a perceived lack of information provided by consultants to patients about their eye condition
- concerns around procedures
- travelling time and cost for patients when travelling to and from the hospitals.

The study also highlighted a low level of patient and their family/friend carers awareness of 4Sight Vision Support and of its Sight Care Advisor service (SCA), and of other sight loss sector organisations such as: Macular Society, Guide Dogs UK, Blind Veterans UK, International Glaucoma Association, Sight Support Worthing or the Royal National Institute of Blind People (RNIB). As part of this study, the internal referral pathway was examined and **there is not a prompt or mechanism for clinical staff working in these eye clinics to refer patients to non-medical support organisations.**

As a result of the evaluation of the patient experience, and a need to ensure any future investment by 4Sight Vision Support achieves the best outcomes for West Sussex residents, Healthwatch West Sussex is using its statutory power to make the following recommendations for consideration by all the relevant statutory health and social care professionals involved in the design, commissioning and delivery of ophthalmology services in West Sussex:

# Recommendations

Many of the common and recurring themes which patient's spoke about could be addressed quickly and with little financial investment. However, to sustain a continuous drive for improvement across the two sites, we would suggest that ***an Eye Health Care Pathway Forum*** is established with membership made up of Consultants, Nurses, Sight Care Advisors (SCAs) and Patient/Carers representatives. The establishment of such a Forum would improve communication between statutory and voluntary sector providers and may result in a reduction in the numbers of patients defaulting to the Eye Clinic when other more cost-effective services are available.

1. WSHFT review waiting times at each of the clinics with a view to minimising the wait for patients and to ensure patients and their family/friend carers are adequately prepared for their clinical experience. For example, **amending the appointment letter** waiting time indication from 2 to 3 hours.
2. Consider installing a **dedicated telephone service for ophthalmic patients**; as many have regular appointments, to reduce anxiety experienced when people do not receive their appointments. Currently, people report it is difficult to navigate the system to chase up appointments, made worse by patients' deteriorating sight.
3. **Review all written communication/templates** to ensure these meet the needs of people accessing the clinics, for example having a minimum of Arial 14 font and then the ability to enlarge the font for individual patients, to ensure the Trust is compliant with the Accessible Information Standard.
4. WSHFT to look at how its **staff can be supported to improve clinical communication**, so patients gain a better understanding of their eye condition and to reduce their stress and anxiety.
5. In line with best practice nationally (including emerging integrated care models and systems), WSHFT reviews the terms and provision of any future SCA service at the Eye Clinics to **ensure that patients benefit from access to community support** as quickly as possible after diagnosis.
6. WSHFT examines its **referral process** from consultants, and other hospital staff, to the **Sight Care Advisors (SCA)** to create a more robust and proactive referral pathway within the Eye Clinics. A simple way of providing information to patients would be to include 4Sight Vision Support & Sight Care Advisors details on all appointment letters and patient correspondence.
7. If 4Sight continues to offer support at the clinics the service works with WSHFT to create a dedicated phone line for the SCA service to support the referral pathway.
8. If 4Sight plans to continue to provide the SCA support, the two organisations identify how to **improve the integration of the services** into the daily work of the Eye Clinics and where appropriate, these staff can confidently contribute to and participate in staff meetings, training sessions and any other opportunities that can help to strengthen the pathway and ensure better outcomes for patients.



9. WSHFT and 4Sight to **review the information on non-medical provision**, to make sure appropriate and relevant services are promoted and accessible to sight loss patients within the Eye Clinic settings. It should be noted that this is already part of the NICE pathway for eye conditions (2018).

The creation and maintenance of an **information stand**, with appropriate booklets of the main eye conditions could support patients in their understanding and self-management of their current and future eye conditions.

10. WSHFT to **review and align car park charges** bands to coincide with the expected length of time patients are likely to spend in the clinic.

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## Acknowledgements

We would like to thank:

- The staff at Southlands and St. Richard's Hospitals' Eye Clinics for the help and support they provided to the two University of Chichester interns during the visits.
- The 85 patients who, willingly gave their time, feedback and personal insights, to help make this study possible.

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## Study rationale

In October 2018, 4Sight Vision Support's Sight Care Advisor (SCA) service celebrated its 20th anniversary.

4Sight Vision Support has provided funding for two (or more) Sight Care Advisors (SCA) roles to work within the Western Sussex Hospitals NHS Foundation Trusts (WSHT) Eye Clinic settings since 1998.

Based in the Western Sussex Hospitals NHS Foundation Trust's Eye Clinics and working in close partnership with the doctors and nursing staff over the years, this service has been making a huge difference to the lives and well-being of over 9,000 visually impaired people in West Sussex.

In the run up to that significant milestone, and with the ambition to evaluate the future sustainability and benefit of an investment in this type of service, 4Sight Vision Support in partnership with Healthwatch West Sussex, commissioned this study.

The partners saw this study as a way of better understanding patients experience of engaging with the Eye Clinics at Western Sussex Hospitals NHS Foundation Trust (WSHFT) Southlands and St. Richard's hospitals and to learn how aware patients were of the SCA service provided by 4Sight Vision Support.

# An introduction to the topic

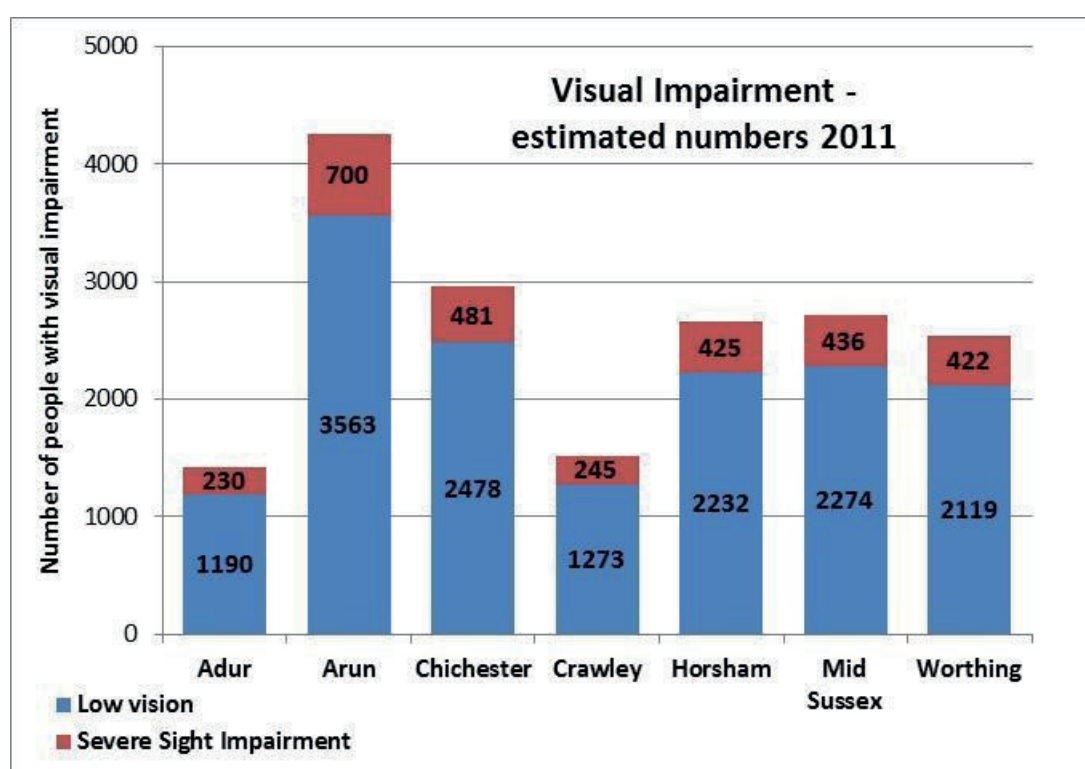
## Visual Impairments Nationally and In West Sussex

Statistics by the Royal National Institute of the Blind (RNIB) (2016, p.10), suggest that over two million people in the United Kingdom live with sight loss. Predictions show that this figure is set to increase by 250,000 in 2020 due to population numbers and aging.

RINB statistics also suggest the population of West Sussex has a higher proportion of individuals with sight loss (3.78%) compared to the South East (3.15%) due to the age structure of our population.

Furthermore, research by RNIB, (2016) found that over 450 children and young adults in West Sussex, ages 0-24 years, has some level of visual impairment.

Figures from the National Eye Health Epidemiological Model (2011) outlined the number of people over 50 years old with visual impairments living in West Sussex.



*Table 1 - Source: National Eye Health Epidemiological Model (2011)*

Although this data is from 2011, RNIB (2016, p.13) reports that the number of people living with sight loss will increase by a third to more than 2.7 million by 2030.

# Adult UK Sight Loss Pathway

Part of the aim of this study was to assess whether Coastal West Sussex (WSHFT) Eye Clinics are fully implementing the Adult UK Sight Loss Pathway (see Table 2 - The Adult UK Sight Loss Pathway)

The pathway charts a personal journey of someone who is experiencing sight loss and sets out the recommended stages eye health care professionals should follow with a patient with a diagnosis of sight loss. The pathway aim is to enhance the information that patients receive, helps to signpost patients and families/friend carers to relevant services and ensure patients are fully supported both medically and non-medically after a diagnosis of sight loss.

The pathway includes the following stages:

1. Referral
2. Diagnosis
3. Early Intervention - advice, information, emotional support
4. Registration & Assessment
5. Early Intervention - reablement
6. Assessment of eligible needs
7. Social care Support
8. Independent Living with full choice and control

As part of the diagnosis stage within the pathway, patients may be offered a Certificate of Vision Impairment and depending on their condition, be classified as either sight impaired or severely sight impaired. According to the Royal College of Ophthalmologists:

The Certificate of Vision Impairment (CVI) Form is for use by the patient or representative, consultant ophthalmologist and hospital eye clinic staff. It formally certifies someone as visually impaired, and acts as a referral for a social care assessment if the individual is not yet known to social services. Its secondary purpose is to record data to be used for research into the underlying causes and the effects of visual impairment.

The College believes that an important component of good clinical care by ophthalmologists is the offer of a Certificate of Vision Impairment to eligible patients and encourages its members to promote the uptake of the Certificate of Vision Impairment amongst patients who are likely to benefit from it and to facilitate the process of registration as far as it is in their power to do so.

For patients, having such a certificate can trigger social services to assess needs and explore resources which aid independence. Registering, as someone with a visual impairment, may provide several entitlements such as: receiving a disability allowance, a tax allowance, reduced fees on public transport and TV license fees and parking concessions.

**In West Sussex, the sensory services team of Rehabilitation Officers for the Visually Impaired will visit anyone struggling with sight loss irrespective of them having a Certificate of Vision Impairment.**

The Adult UK Sight Loss Pathway has been developed in association with health and social care and was established to increase partnership working. The pathway has been accepted by the Strategic Advisory Group of the UK Vision Strategy which advises local authorities, GPs, ophthalmologists and all other professionals in the eye health sector, who support its usage.

## Research on Visual Impairment

According to the World Health Organisation (2015), visual impairment can be described as:

Sight loss that is uncorrectable by glasses, contact lenses or surgery with the most common causes in the UK being Age-related Macular Degeneration (AMD), Diabetic Retinopathy and Glaucoma. The World Health Organization acknowledges that these three conditions are the most common cause of sight loss in industrialised countries across the world.

Being registered as *Severely Sight Impaired* does not necessarily mean the person will have no vision whatsoever, the vast majority of people registered, have some vision, although it may be very limited.

For example, someone with AMD will lose their central vision and this affects their ability to read, see facial features and discriminate near objects but they will still usually maintain peripheral vision, which helps them with navigation.

Conversely, someone with tunnel vision due to glaucoma may still be able to read small print but their loss of peripheral vision makes crossing the road hazardous and steps and kerbs are difficult to navigate and it is this loss of peripheral vision that makes them eligible for Severely Sight Impaired registration.

Sight loss or visual impairment can be inherited or obtained at any age and can affect people in many ways and be potentially life-changing. Sight loss can affect how people move around and access information. In the UK, uncorrectable sight loss is most frequently caused by age related conditions, some of which may have a hereditary link and can have a profound effect on an individual's ability to live independently.

Research by Saeed and Saleem (2017) explained that low vision is correlated with negative outcomes such as decreased mobility, reduction in performing daily tasks and even depressive symptoms. Sight loss can also affect a person's independence as they become more reliant on others for assistance and find it hard to care for themselves (Brown et al., 2014). Furthermore, daily activities such as eating, dressing, shopping, medication administration, driving, reading, socializing and financial management may become difficult to perform



(Whitson et al., 2014). Vision impairment can also affect educational aspirations and employability (Douglas, Pavey & Corcoran, 2008).

As sight loss is often linked with ageing, individuals frequently have other co-morbidities which increases their vulnerability (RNIB, 2012). Finally, a study by Crews, Chiu-Fung Chou, Stevens, and Saadine (2016), found a higher prevalence of falls (46.7%) among people over 65 years with severe visual impairment compared to individuals without such impairments.

This evidence, alone, highlights the potential impact of sight loss on independent living skills experienced by visually impaired people and the difficulties they may encounter adjusting to their daily living activities. **The impact on quality of life can be greatly underestimated by medical professionals and the promotion of non-medical services should become a key component of the Eye Health Care Pathway to enhance independence, self-esteem and improve mental health and wellbeing.**

## **4Sight Vision Support Sight Care Advisors role**

Saeed and Saleem (2017) stated that the majority of patients with sight loss need some sort of psychological support, however, they may not receive it due to a lack of knowledge and inadequate services being available. To counter this, it is important that organisations that support people with sight loss are properly promoted thus enabling access to prompt advice, support and guidance at a critical point in each patient's sight loss journey.

4Sight Vision Support is a charity organisation based in West Sussex which works to support individuals (including families, parents, carers) affected by sight loss. Annually, the charity provides a range of services to approximately 4000 people in the county who receive guidance, advice, social support and visual aids to ensure they remain as independent as possible. 4Sight Vision Support has employed Sight Care Advisors since 1998 in the WSH hospital eye clinics of St. Richard's and Southlands Hospitals (and Worthing Hospital before that) to provide emotional, non-medical support and appropriate information to patients.

Since the Sight Care Advisor service began at Western Sussex Hospitals Trust there have been over 9000 contacts made with patients via telephone, email and face to face. On average the SCA service directly helps with the registration process of over 330 people a year as either Sight Impaired or Severely Sight Impaired although many more patients receive SCA support, advice and guidance - something that is also extended to professional colleagues both in the hospital and the community.

In addition to their role in facilitating the CVI on behalf of patients and supporting patients with their appointments and acting as 'Patient Advocates' and 'Patient Champions' more generally, the Sight Care Advisors frequently act as the gateway to Low Vision Services that are provided by specialist opticians locally on behalf of the NHS Trust. They provide patients with the information, contact details and the Hospital Eye Services voucher required to obtain their Low Vision Assessment and magnifying aid which is a vital piece of equipment enabling a degree of independence.

# Eye Care Pathway

## Adult UK Sight Loss Pathway

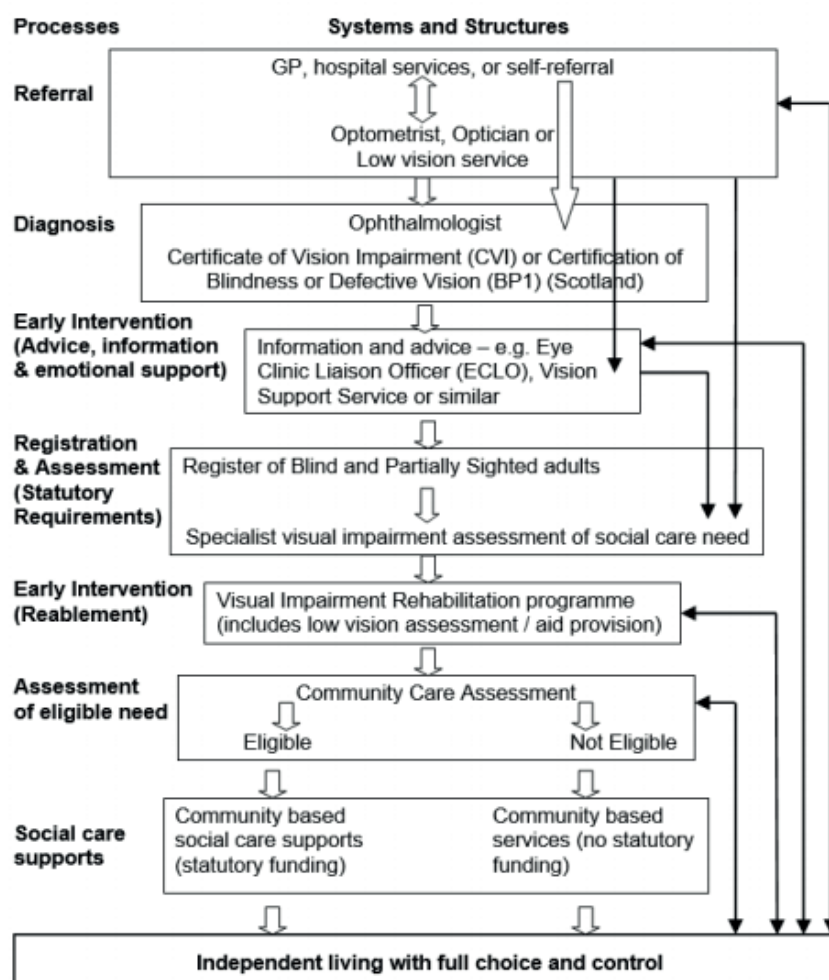
Table two illustrates the suggested sight loss pathway for UK adults. Based upon the evidence of this study, it can be inferred that not all patients who attend the eye clinics of Southland and St. Richard's hospitals are routinely referred to the Sight Care Advisors at the eye clinics by the medical staff, therefore limiting the opportunity for support and information a patient receives at critical points in their sight loss journey.

According to the Sight Care Advisors who were interviewed, most patients being registered for a sight impairment are referred by their consultant to the Sight Care Advisors immediately after their appointment, which enables them to provide immediate advice and emotional support, at what can be a very frightening time.

The study shows there are instances where patients whose sight loss means they are currently not eligible for registration, but are struggling with sight loss, are slipping through the net of being offered timely support and guidance.

To counter this, the Sight Care Advisors operate an 'open door' policy, encouraging anyone experiencing difficulty to contact them, regardless of their level of sight loss and whether or not they are being seen in the clinic.

**Table 2 - The Adult UK Sight Loss Pathway**



N.B. Children with low vision require referral to the LVHRS as soon as possible.

# The Study

This study is the product of a partnership between 4Sight Vision Support, Healthwatch West Sussex and The University of Chichester University. Through their GraduateOn scheme, the University identified two interns who were trained by Healthwatch West Sussex in the *Enter and View* processes and had the status of *Authorised Representatives* during the course of the study. They were then introduced to the teams at the Eye Clinics at Southlands and St. Richard's hospitals' Eye Clinics.

The study used a specific questionnaire to capture views and comments. Those who consented to be involved in the study were interviewed, whenever possible in a quiet, private room away from the clinic waiting area.

The study included 22 questions about the patients' eye condition, their experience at the Eye Clinic and living with an eye condition, the support they received initially and after diagnosis provided by the two eye clinics, and about the support (if any) that patients had received from other community organisations such as: 4Sight Vision Support, Macular Society, and the RNIB. The interviews occurred during the period July 12th and August 17th, 2018.

Through a process of listening in a safe and supportive environment, the study could capture patients experiences in more detail.

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## Data Collection

The Interns interviewed people visiting Southlands and St. Richard's hospitals for thirteen days. They spoke with patients randomly as they were waiting for their appointment or after their appointment. Clinic staff supported the recruitment of patients for the study.

Each questionnaire took between 10-15 minutes to complete. All patients gave verbal consent to take part in the study (seen as more appropriate for the patient group, e.g. sight loss and reading issues), after being informed of the content and that the information given would be anonymised in a report.

Participation in the study was voluntary, with no active follow up. 85 patients were interviewed as part of this study.

We acknowledge some patients were interviewed before their appointment with a consultant and that those people may have answered their questions differently if they had been interviewed after their appointment.

# Findings

## Study Demographics

Study participants ranged in age from 55 to 89 years, with a mean age of 80 years. The survey questionnaire included information about the patient's demographics, see table 3.

*Table 3: Survey demographics*

Survey demographics		
Gender	55% (47) female	45% (38) male
Employment status	96% retired and 4% employed	
Ethnicity	96% white British and 4% Italian and Romanian	
Other health issues besides eye problems	Diabetes, Cancer, COPD, Arthritis, Rheumatoid Arthritis, Osteoporosis, Asthma, Multiple Sclerosis, chronic pain, and Heart Condition	

## Identification of Eye Condition

Most participants' eye condition (70%) had been identified by their optician, 20% were aware of a change in vision, and 10% were identified from routine checks for another long-term condition or had experienced a long-term eye condition for many years.

### Identified by Optician

I went to the opticians as the sight was getting a little grey. My routine eye check had been in March 2017 and before my next routine appointment. I went to Vision Express who informed that I had a bleed behind the eye and they rang the hospital and I had to go straight there. They then referred me to this clinic. They confirmed that I had had a bleed in both eyes and thought this might be due to hypertension. I went to my GP and he gave me medication. In April I had a cataract operation.

I was referred via a routine optician appointment this was September 2017. I was seen in January 2018 for assessment for a cataract operation. The operation was in February 2018. In the March I was re-assessed and there was a swelling behind the eye and in April I had an injection and May was seen by the

consultant. I had suspected that there was a problem about 6 months before the optician referral.

I went to my optician for a routine check-up and they identified my eye condition, this was about 2 years ago. I visited the hospital initially every 4 weeks then every month and now with 10 weeks between visits. 'I am amazed that anything can be done about it'.

### Identified by Self-referral

I thought something was wrong as I had black dots and the optician referred me to the hospital. This was about 2 years ago.

I went as my right eye was seeing blurred. I have been at the eye clinic for 2.5 years.

I have Glaucoma and was under St Richard's hospital, I saw the doctor there and had an eye test and was then sent for a scan as I was having a bleed at this time. The consultant told me 'It was a bad bleed and I needed to be seen immediately'. That was in August 2017. My condition has improved since August 2017.

I just began to have difficulty with my sight and was sent to Goring Hall some years ago. There was a long delay and then I was told to leave it for 6 weeks, but the sight has deteriorated since my last appointment. I was at St Richard's hospital last week and they sent me here. 'My eye sight deterioration is a worry - everything is black in the morning and gradually gets better as the day goes on'. 'I would really just like to see better than currently.

### Identified by Referral Other

I had an eye check as my father had glaucoma and I was on regular checks. This was about 20 years ago.

My eye condition was located at the diabetic annual check-up about 4 years ago.

I went for my normal diabetes check-up at Littlehampton clinic in 2018. I was told that the eye condition was getting worse and sent to Worthing diabetic eye clinic for a check. The optician wrote a very long letter to this clinic. This was about 2.5 months ago. I have an eye check-up because of diabetes normally only once a year but this year twice.



## Visits to The Eye Clinics In Past 12 Months

68% of the study group reported attending the eye clinic less than five times in the past 12 months and 32% more than 5 times in the past 12 months. Many had pre-booked appointments ranging from 2 weeks to 6 months or annually.

Due to the long-term treatment required for some conditions, many patients had pre-booked appointments and had been sent a reminder letter, a few weeks before the appointment.

Around 80% of patients were very happy with this process.

I attend the hospital ever 4 weeks. The hospital writes to me with an appointment between appointments.

The first appointment was at Worthing hospital and the tests were done well and they identified another condition - which I can manage myself.

Normally I come every 6 months it has been 3 months since the last appointment.

The process has been smooth.

However, approximately 20% said they had not experienced a smooth appointment process.

You do have to wait a long-time during appointments but when you see someone they are very supportive.

Although it was the Christmas period when I had the bleeds and there were delays due to the Christmas holidays - as nothing gets done over this period if not urgent or life threatening (Nov 2017).

This suggests there is a need for the Trust to review its ophthalmology communication (standard templates) and information leaflets to make sure these are fit for readers with sight loss. The use of Arial 14 would seem a minimum requirement, with the ability to amend the font size according to individual patient need. The introduction of a reminder telephone call/ text, or email, would help patients.

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## Summary of Patient Experience

Many people reported an overall satisfaction in the service they received, from initial diagnosis to current treatment Southlands and St. Richard's Eye Clinics. People reported hospital staff had supported them very well, that the environment felt safe and they were very well looked after during surgical procedures. Patients were appreciative when staff called them to check how they were feeling a few weeks after a procedure.

The hospital gives good experience and the consultant is supportive.

They are much better than Worthing hospital was - they talk to you, tell you what is happening, and the room is so calm.

The staff are very nice and helpful.

Several patients reported that the appointment system was confusing and needs to be reviewed. People suggested all appointments had a telephone reminder and that it would be easier if their next appointment was made prior to them leaving and within the timeframe suggested by their consultant.

## Waiting Times Between Appointments

Several patients reported having problems with appointments. These ranged from cancellations, appointments not being given within timeframe suggested by consultants, no appointment letter or telephone call received.

Patients also said appointments tended to take longer than stated on the appointment letter and the overall process for appointments was confusing.

I had my appointment for May and this got cancelled 5 times (one date twice) it has taken since May to get this appointment (now August).

It can be difficult to get an appointment as the doctor says he wants to see you in 6 weeks and you do not hear anything. I had to chase them for this appointment and waited 2 weeks. There was no letter or telephone call. After I phoned them the letter arrived and I am here today. This means 8 weeks between appointments.

The booking system is confusing for the appointments in January and February I received a letter, and the next one I did not receive anything. I phoned up and was informed 'you should have been here this week'. I then received two letters one dated 21st March and one dated 22nd March. So, do I book when I leave or leave it 2 weeks and then phone up so that it does not get forgotten. Wednesday was the first time I have received a telephone call from the hospital.

## Time in Clinic

A few patients reported positively on their experience of their clinic waiting times.

It is good that you do not have to wait too long, and it is smooth moving from one room to another.

You do have to wait a time before being seen but I accept this.

The hospital gives good experience and the consultant is supportive.

The clinic is fantastic. The nurses were fantastic and very efficient.

Clinic **waiting time** for most were an area of concern.

The last time I came here it took 3 hours.

I think the clinic is slow my appointment today was 1.50 and it is now 15.10 and I have not yet had my injection. They seem to only start on the injections once there are 8-9 patients waiting. So very slow.

This is my 3rd appointment. I was here early 9.45 and my appointment was 10.15 it is now 11.00 this is the worse I have had to wait, they are normally better than this.

I came to one appointment here in the afternoon and was here from 1-4.30 (3.5 hours) and the injection takes 5 minutes.

## Communication Between Healthcare Professionals and Patients

Several people reported that healthcare communication was poor, as they were not told what their eye condition was or the prognosis. These people felt they needed more explanation of procedures so that they knew what to expect and the could plan.

It would be good if there was some continuity of doctors, as you should see the same person who has done the operation as they know you - I know they do 100s of operations and you like to think they will remember you. This would also stop having to explain things over again.

When I asked the doctor about the eye condition he ran out of the room to get a nurse. He said he had written a report letter, but no-one has seen it. I got the opticians to follow up for me.

Today was supposed to have been an appointment for both eyes but they have only put out one file and not two - this has happened many times. Worthing lost the files completely.

Mom was referred to the hospital by her optician. The doctor assumed that mum know about her eye condition. It is important that they check what patients know about the condition.

## Information Received About Eye Condition

88% of the study group felt they were informed about their eye condition and future treatments.

Leaving 12% saying that although they had attended appointments their understanding of their own condition was not checked by consultants, and they felt embarrassed to ask too many questions.

You only get a few minutes and it can be a worry about the injection and I need more reassurance.

The doctor doing the procedure was talking to me all the time and this was reassuring.

Patients need much more information about the condition. It would have been good to have had this information on the first appointment to take away. There is an assumption that after the initial assessment that you know about the eye condition, there is not enough information being provided. I think it would be welcome to receive information about the condition at the beginning when first diagnosis to support.

One patient suggested that it would be helpful if the doctors discussed and summarised the details of the previous visit and current visit for clarity. Several patients felt that upon diagnosis they needed to be given accurate information about the condition and not to have to research information themselves.

We have concluded from peoples' experience that there is a need for more explanation, hard copy condition specific information and referral to specialist eye support organisation such as 4Sight Vision Support, Macular Society, Guide Dogs UK, Blind Veterans UK, International Glaucoma Association, Sight Support Worthing or RNIB.

It was also suggested eye clinic staff use less jargon.

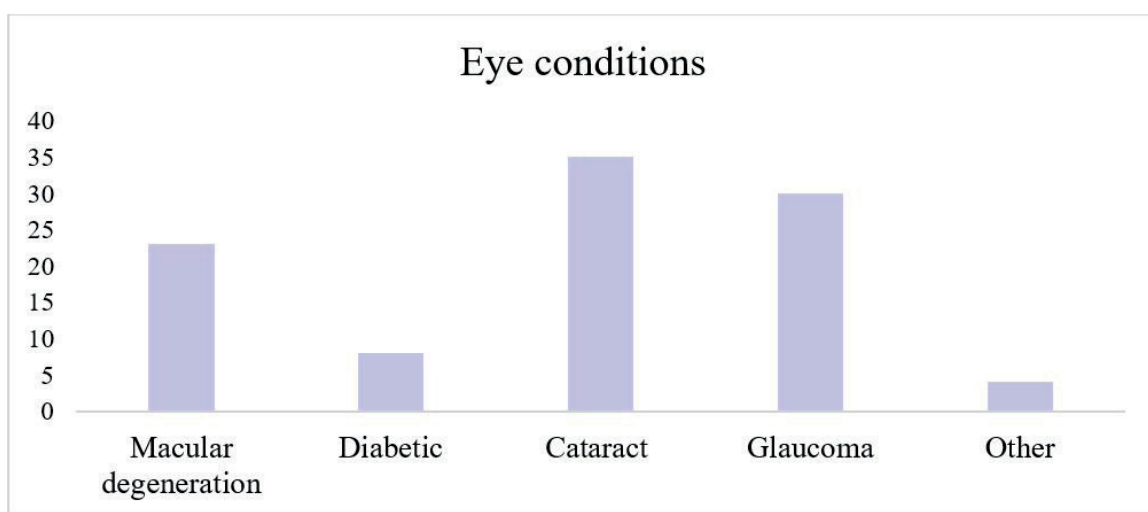
I needed more information and the consultant said that after the second scan she would discuss what treatment was needed. This did not occur I just got an appointment and no information, so did not know what to expect. I was not informed what would happen once the melanoma was removed and then my eye got infected. I have not received a great deal of support, not as much as I should have.

I was not told anything about what I should do to help, if I should take supplements or wear dark glasses - I read that this is helpful in a magazine. They do not tell you anything, so information would be useful.

They seem to give very scant information and in a format that is not easy to understand, patients do need more information. We had to ask for leaflets as none are available.

## Main eye conditions presented

Many patients were receiving treatments for more than one eye condition. This study was not designed to answer if there is a relationship or trend with the number of eye conditions and age, but other research would suggest there could be.



*Figure 4 - Eye condition/s receiving treatment for*

## Travelling to the hospital

Many of the patients did not find travelling to the hospitals a major issue as they had family/friends to support them, or they got taxis. However, many family members had to take time off work to support them.

Those who had to use public transport did find difficulties especially for early appointments, or found they had to catch earlier transport to get to their appointment on time. This meant that a whole day needed to be set-aside, yet many appointments were for a very short-time.

My son has bought me, and he lives in London as I am unable to come on my own.

I have my special friend.



My son bought me. It is difficult as I am housebound. I did enquire about a taxi and it would cost £50 round trip. This is a lot of money when on a pension. It has been suggested that I contact my GP to provide transport. I cycled here as close to home. However, they do need somewhere to lock up your bike.

This is a problem as to get the Bus it takes 2.5 hours, and this is impossible as you could miss the appointment. If I travel by train someone has to pick me up - as I can cycle, there but not back - I need collecting.

Another area of irritation was the cost of parking at the hospitals.

I have put 2 hours on the car parking machine and I am not going to see anyone by 11.30 and will have to go as I have another appointment.

I do not mind paying for how long I need but I do not know how long I need. The costs of parking are very high.

## General experience of attending the eye clinics

People were asked to suggest possible areas for improvement. Generally, patients were happy with the system and processes, with the exception being the waiting time. One reason being that this did not just affect the patient but also those who were assisting them.

The last time I came here it took 3 hours.

It would be helpful if the hospital had better timings for appointment.

Most people who parked their car in the hospital car park were very upset that the result of a late appointment meant having to pay extra for car parking.

Car parking also appeared to add the stress of possibly missing being called whilst adding more time and not knowing how long to add.

People suggested there needs to be a better system in place or better communication as appointment letters indicate only 2 hours.

It was also suggested that a review of waiting times was needed to manage customer expectation, something that is as important for hospitals as other service areas.

In addition, one patient shared that there should be better directions given by staff to navigate around the hospital, as when he comes to the hospital, he was directed to his appointment by being told to walk through the green doors or sit on the purple chairs both of which were difficult for him, because his vision was poor.

## 4SIGHT Vision Support / Sight Care Advisor Service

As part of the study, patients were asked about their awareness of 4Sight Vision support and of the Sight Care Advisor service, which has been provided free of charge by 4Sight Vision Support to support the staff teams at both Eye Clinics for the past 20 years.

Of the 85 patients interviewed only 5% were aware of 4Sight Vision Support, and none of the participants were aware of the Sight Care Advisors based in the Eye Clinics at each site.

No, I have not heard of Sight Care Advisor but then I do not need them at present. It is good to know they are there for the future. At present I am ok and as the sight is a silent thing this will change in the future I guess.

Yes, I have heard of them, they are based in Bognor. I do not know what a Sight Care Advisor is.

I was referred to 4Sight by the opticians.

I was not signposted by the medical staff to the Sight Care Advisor.

We acknowledge that, for a variety of reasons, it is possible patients may have been through the Sight Care Advisor service without knowing the staff were called Sight Care Advisors and may only have been aware of the Sight Care Advisor on first-name terms.

Equally, it is possible that for some patients interviewed, they were unaware of the Sight Care Advisor service because their vision was not deemed to be at a level that they needed to be referred by their consultant for support.

Many felt the hospitals should be providing them with more information about their eye condition and of the other non-medical services in the local area. **Evidence shows that good information supports people to live well on a day to day basis.**

The condition means that I am unable to read newspapers even with plenty of light and sitting close to the TV, I am also unable to drive. You do not realise how much you use your eye for things, reading, driving. The other day I put my credit card into a machine and could not see the numbers, the assistant must have thought here's someone dodgy.

I cannot do cooking which I did enjoy doing previously and I have to get someone to get the cobwebs down.

It is a struggle really, slowly things are getting back to normal. I am unable to drive, and wet shaving is a challenge (due to loss of perspective) I am unable to see out of the eye and find things very bright so wear sunglasses.

The condition is embarrassing, and I feel so old as it should be an older person's condition.

## Experience and Support

Only 2% of the participants were registered as visually impaired.

Most said they had not been referred for a Low Vision Assessment, but when we changed the terminology and asked people if they had been supplied with magnifying aids, 9% responded they use magnification aids.

When asked about this subject, the SCAs stated that it is important to remember that the use of medical terminology with patients can be confusing, for example, the term “Low Vision Assessment” is unlikely to be known (or remembered) by many patients whereas “magnification/magnifiers” is more likely to be understood.

According to feedback from the SCAs, all patients who are registered visually impaired are offered a Low Vision Assessment but may have either declined to have one, forgotten they had had one or didn't understand the terminology used in the question.

95% of the study group (81 out of 85) were unaware of local non-medical support services available to visually impaired people living in Sussex. When the interviewers gave them information on such services 34% of patients said they appreciated having this information now for the future.

Many participants felt they were coping with day to day things with the support of family members and others. But felt it would be helpful to have information about local organisations such as 4Sight Vision Support, Macular Society, Guide Dogs UK, Blind Veterans UK, International Glaucoma Association, Sight Support Worthing or RNIB who can provide information about their eye condition, aids and peer support.

Many felt that more information should be available when first diagnosed through the Eye Clinics, with more condition specific information available in a printed accessible format.

Many found it reassuring to hear the Sight Care Advisor service was available to them for support, signposting and further explanation of their sight condition and asked why their consultant had not referred them to the Sight Care Advisor as part of the eye clinics pathway.

**Patients stated they felt that emotional support was ‘as important as medical support’,** to help patients make the necessary adjustments to living well and independently. Many were struggling with their change of vision with everyday things such as reading, watching TV, shopping, going out and transport.

# Conclusion

In conclusion, the study has shown that generally patients reported a satisfaction with the service at both Eye Clinics'. Although, there are reported issues around appointments, length of time in clinics, poor communication between healthcare professional and patients, lack of information provided about their eye condition and about procedures. The study has highlighted that only 5% of the study group had heard of 4Sight Vision Support or of the Sight Care Advisor service. This is of concern as several of the study group commented about the lack of non-medical support they have received.

The recommendations on pages 2 & 3 should help the Trust and the organisations supporting local residents through their sight loss journey to improve peoples' emotional wellbeing and practical experiences.

## Next Steps:

Our next steps are to share the report with the Trusts and to work with them to support the proposed changes.

# Working in Partnership



## Making a positive difference for people living with sight loss.

For nearly 100 years, 4Sight Vision Support have been the leading sight loss charity supporting the visually impaired community of West Sussex. Sight loss can happen to anyone of us at any time. Everyday 250 people in the UK begin to lose their sight. Today there are 30,000 people with sight loss in West Sussex alone.

At the heart of our holistic & person-centered services is a commitment to ensuring that a diagnosis of sight loss is not a one-way road to loss of independence and isolation. 3000 members and 300 volunteers create a community that inspires and mentors its peers to maintain and transform their own lives into positive and fulfilling ones after sight loss.

**We have a simple ambition, at Healthwatch West Sussex... to make local health and social care services better for people that use them. We are here to listen, take action and influence positive change for local people living in West Sussex.**

We record what people tell us and share this anonymously with those who make decisions about our health and care services.

**You can contact us in several ways:**

Telephone: 0300 012 0122

Email: [helpdesk@healthwatchwestsussex.co.uk](mailto:helpdesk@healthwatchwestsussex.co.uk)

Website: [www.healthwatchwestsussex.co.uk](http://www.healthwatchwestsussex.co.uk)

You can also follow our social media channels to always be updated with the latest in health and social care news across West Sussex: [Facebook](#), [Twitter](#).

**Healthwatch is transparent and independent, with the authority to demand action. Together we speak louder.**

### Chichester University

**“The University of Chichester is keen to work collaboratively with local organisations and values their commitment to providing career enhancing work experience opportunities to our students.”**



## Visual Impairment Community Organisations

### Blind Veterans UK

[www.blindveterans.org.uk](http://www.blindveterans.org.uk)

Tel: 0800 389 7979 Email: [information@blindveterans.org.uk](mailto:information@blindveterans.org.uk)

Blind Veterans UK offer lifelong support to Armed Forces and National Service veterans no matter what the cause of their sight loss, and regardless of how long they served. They help blind and vision impaired ex-Service personnel regain their independence and discover life after sight loss.

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### International Glaucoma Association

Tel: 01233 648 170 Email: [info@iga.org.uk](mailto:info@iga.org.uk)

[www.glaucoma-association.com](http://www.glaucoma-association.com)

The IGA is the charity for people with glaucoma. They provide information, literature, advice and fund essential research to prevent unnecessary loss of sight through early-detection, diagnosis and treatment. They also run campaigns to raise awareness of the need for regular eye health checks to detect the 300,000 estimated to be living with undetected glaucoma in the UK today.

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### Macular Society

Tel: 0300 3030 111 Email: [help@macularsociety.org](mailto:help@macularsociety.org)

[www.macularsociety.org](http://www.macularsociety.org)

The Society provides support to eyecare professionals to enable them to help their patients. This is achieved through free accessible patient information, online training (CET/CPD-accredited) and a Helpline, as well as a network of almost 400 local support groups. Their services are accessible through the free Macular Society app for Apple and Android.

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### The Guide Dogs for the Blind Association

Tel: 0118 983 5555 Email: [guidedogs@guidedogs.org.uk](mailto:guidedogs@guidedogs.org.uk)

[www.guidedogs.org.uk](http://www.guidedogs.org.uk)

Supporting over 5,000 Guide Dog owners in the UK, as well as offering a range of services and activities for children & young people and providing advice to parents and teachers.

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### Royal National Institute of Blind People (RNIB)

Tel: 0303 123 9999 Email: [helpline@rnib.org.uk](mailto:helpline@rnib.org.uk)

[www.rnib.org.uk](http://www.rnib.org.uk)

The Royal National Institute of Blind People (RNIB) is the UK's leading charity supporting people with sight loss. They offer practical, emotional, employment, technology and welfare benefit support to those that need it, so they can continue living life to the full.

**Sight Support Worthing**  
**Tel: 01903 235782**  
**Email: [info@sightsupportworthing.org.uk](mailto:info@sightsupportworthing.org.uk)**  
**Web: [www.sightsupportworthing](http://www.sightsupportworthing)**

Sight Support Worthing is the operational name for Worthing Society for the Blind, a registered charity and one of the longest surviving independent charities in Worthing which was founded in 1910. Worthing Society for the Blind rebranded to Sight Support Worthing in 2016 in the hope of attracting more members and extending its services to those who would benefit from the activities, advice and support that it can provide. The aims of the charity are to promote the relief, general welfare, entertainment and provision of services, for persons who have sight impairment and are living within the Borough of Worthing.

**4Sight Vision Support**  
Bognor Regis Vision Support Centre  
Bradbury Centre  
36 Victoria Drive, Bognor Regis, West Sussex, PO21 2TE  
**Main Tel: 01243 828 555 Fax: 01243 838 003**  
**Email: [enquiries@4sight.org.uk](mailto:enquiries@4sight.org.uk)**

4Sight Vision Support have been the leading sight loss charity supporting the visually impaired community of West Sussex. Sight loss can happen to anyone of us at any time. At the heart of our holistic & person-centered services is a commitment to ensuring that a diagnosis of sight loss is not a one-way road to loss of independence and isolation. 3000 members and 300 volunteers create a community that inspires and mentors its peers to maintain and transform their own lives into positive and fulfilling ones after sight loss.

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