

# 555

## Sensory Impairment Project

'My impairment is my  
deafblindness. My  
disability is what other  
people make of it.'

555 participant

Capturing the lived experience of people with  
a sensory impairment who access and use  
health and care services in Essex

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## Acknowledgements

We are really grateful to of the participants who gave up their time to attend the 555 Sensory Impairment focus groups, and in particular the five individuals who shared their own lived experience at the ‘Love Your Senses’ event on 14th February 2017.

By sharing your experiences of accessing and using health and cares services in Essex, you have already made a difference.

Thank you to ECL Sensory Service who were instrumental in this project. Also to the Royal Association for the Deaf, Support 4 Sight, Essex Sight and Hearing Help Essex, who hosted our focus groups and gave us access to their service users and clients.

Please note that names have been changed to protect identities. Where we have used direct quotes in the report, the sensory impairments attributed to each participant have been noted in the way in which they wish to be classified.

# Introduction

Our award-winning '555' model of engagement is recognised both locally and nationally as an innovative, and yet simple, means of capturing the lived experience of people in Essex, and giving them the opportunity to share their stories, face-to-face, with professionals who deliver care throughout the county and beyond.

Between October 2016 and February 2017, Healthwatch Essex undertook the engagement work for this 555 project, focussing on people with a sensory impairment. We have worked with a range of sensory organisations, including ECL Sensory Service, Royal Association for Deaf People, Support 4 Sight, Essex Sight, Hearing Help Essex and Inclusive Communication Essex, to access individuals who are visually impaired, hearing impaired, Deaf or deafblind. Our aim was simple: to listen and to find out about their lived experience of accessing and using local health and care services.

There are currently over 180,000 people living with a sensory impairment in Essex.<sup>1</sup>

The majority of people who are registered as having a sensory impairment are over the age of 65. As the population ages into the future, there is likely to be greater demand on services to support the needs of people with sensory impairments.

This project is also timely as it coincides with the implementation (and review) of the Accessible Information Standard introduced by NHS England, which aims to provide people who have a disability, impairment or sensory loss with information that they can easily read or understand.



On 14th February 2017, we invited commissioners, clinicians and providers to attend an event in Essex, to listen to the lived experience of five individuals living with a sensory impairment.

<sup>1</sup> Data supplied by ECL Sensory Service

This report brings together the voices of ordinary people living in Essex with a sensory impairment and shines a light on their experiences of accessing and using health and care services. It offers a perspective on their experiences, as well as suggestions on how they felt, what worked well and what could be improved.

This report is directed at those professionals responsible for designing, commissioning and delivering services in Essex. Listening to people living with a sensory impairment is the first step to shaping services that are fit for purpose, financially sustainable, and above all, in the best interest of the people.

Together, we hope that sensory impaired health and care service users (and their carers) in Essex will feel secure in the knowledge that with the right support and information in their preferred format, they can continue to live life to the full.

Living with any condition or impairment puts people in a unique position – they become the expert of their own experiences.

**Now is the time to listen to the experts.**

**Dr Tom Nutt**

Chief Executive Officer, Healthwatch Essex

## How we engaged

Using the 555 model, Healthwatch Essex worked with ECL Sensory Service, Support 4 Sight, the Royal Association for Deaf People, Essex Sight, Hearing Help Essex to host a series of focus groups across Essex to listen to the voices of people with a sensory impairment or a dual sensory loss.

Anyone over the age of 18 and living in Essex could attend the groups and we met and listened to **79 people** over the course of a month. 65 of these people were living with some form of sensory impairment, and fourteen people offered support or care to others in a significant way. We also received information from a further **31 people** who were living with, or cared for someone with a sensory impairment, from our online survey.

This report sets out the findings from this exercise.

# Method

We held focus groups across Essex between October and November 2016, engaging with 65 sensory impaired people and 14 people who offered care and support. We also conducted an online survey to which a further 31 people contributed. The focus groups were held in:

- Chelmsford – ECL Sensory Service – 20th October
- Chelmsford – Hearing Help Essex – 2nd November
- Colchester – Essex Sight – 8th November
- Clacton – Essex Sight – 17th November
- Colchester – Royal Association for Deaf People – 22nd November
- Chelmsford – Support 4 Sight – 30th November

## Participants represented the following areas:

- Chelmsford
- Witham
- Writtle
- Great Leighs
- Ingatestone
- Basildon
- Colchester
- Hadleigh
- Braintree
- East London
- Tiptree
- Brentwood
- Clacton
- Saffron Walden
- Takeley
- Hockley
- Leigh on Sea
- East Hanningfield
- Billericay
- Harwich
- (two participants from Suffolk)

## Services accessed:

- GP
- Dentist
- Low Vision Clinic
- Audiology Departments
- Southend University Hospital NHS Foundation Trust
- Addenbrooks Hospital
- Braintree Community Hospital
- Moorfields Eye Hospital
- ECL Sensory Service
- Princess Alexandra Hospital
- Adult Social Care
- Broomfield Eye Clinic
- Broomfield Hospital
- Queens Hospital Romford
- Colchester Hospital University NHS Foundation Trust
- Springfield Clinic
- Hearing Help Essex
- Basildon and Thurrock University Hospitals NHS Foundation Trust
- Support 4 Sight
- Essex Sight
- Royal Association for the Deaf

## Participants had the following sensory impairments:

- Deaf or hard of hearing
- Sight impaired or severely sight impaired
- Deafblind

## Conditions linked to, or causing the sensory impairment:

- Stroke related eye conditions
- Retinitis Pigmentosa (RP)
- Diabetic Retinopathy –  
Diabetic Macular Oedema
- Age-related Macular  
Degeneration (AMD)
- Chronic Glaucoma
- Congenital Glaucoma
- Marfan Syndrome
- Cataracts
- Charles Bonnet Syndrome
- Dry Eye Syndrome
- Nystagmus
- Retinal detachment
- Hearing loss due to Meningitis
- Hearing loss due to German Measles
- Tinnitus
- Hydrocephalus
- Usher Syndrome
- Ménière's Disease
- Nystagmus Ocular Albinism
- Auditory Processing Disorder
- Macular Degeneration (tdry)
- Myopia
- Progressive Degenerative  
Optic Atrophy
- Cochlear Otosclerosis

## We spoke to:

Males – 23

Females – 56

## Respondents to our online survey:

Males – 9

Females – 19

Prefer not to say – 3

We asked participants for their consent to take part and for their response to be shared. By working with our partners, we ensured that the participants had appropriate support in place to enable them to participate fully.

## What we asked

We asked the participants about what services they currently access, what worked well and not so well for them and what they valued. We also asked them if they had heard about the Accessible Information Standard and whether they currently received information from health and care organisations in their preferred format.

# Key findings

Although our engagement with sensory impaired people covered a range of health and care services, recurring issues emerged from the sensory impaired participants' lived experience that seemed consistent across all services.

It is our belief that - by exploring these issues, recognising the impact of each and acting upon it during booking and attendance at appointments, referrals, discharge and follow-ups – we can change health and care services for the better, and provide a more positive health and care experience for individuals living with a sensory impairment.

## What people told us

In summary, we found that the majority of participants:

- Had experienced difficulties in making appointments with health and care service providers, particularly GPs and outpatients, as the booking systems in place were considered inflexible.
- Felt their sensory impairment was not always recorded well on their records, and that this information was not shared effectively between and within service providers, which meant that their support needs were sometimes not met.
- Thought that the approach to accommodating patients with sensory impairments, in terms of accessibility, was inconsistent across service providers.
- Did not currently receive information and communication in their preferred format.
- Did not want to have to rely on family members or carers to access services, as they felt this was not only an inconvenience, but also, in some cases, could impinge upon their right to confidentiality.
- Felt that there was a general lack of awareness and understanding by staff (and especially receptionists) of their sensory impairment and needs.
- Didn't tend to make complaints about service providers, as they either didn't think it would be worthwhile, or felt they might it compromise their future care.

## What they valued

- Being treated as an individual and consequently being able to take control of making and attending appointments, where possible.
- Not having to repeat their story at each consultation.
- Being asked if they needed assistance.
- A friendly and helpful attitude by staff.
- Being able to understand the information given to them, in a format that's suitable for them. And being able to communicate back in that way.
- Having a bit more time at their appointments.
- Feeling comfortable, not anxious, in the waiting room, knowing when it's their turn, and knowing that their support needs will be met.

It was commonly reported that not being able to understand what is being said, not receiving information in the preferred format or not having the necessary support in place for an appointment could have a serious effect on an individual with a sensory impairment. In particular, people reported a loss of autonomy and confidentiality, and a negative impact upon dignity and quality of life.

## Loss of autonomy and confidentiality

**'Just ask me what I need or if I'm ok. Treat me as an individual.  
I may be blind, but when I lost my sight, I didn't lose my mind'**

**Blind participant**

The loss of autonomy and confidentiality was a key finding that emerged throughout the study, no matter the sensory impairment. The difficulties, and barriers encountered, when trying to access health and care services had a negative impact on individuals' independence. Participants felt that they did not always have control over their own health or care needs and wanted to be treated as an individual. They wanted to feel confident in being able to book and attend an appointment on their own (where possible), and that their sensory impairment was taken on board when they tried to access services. Relying on carers or family members to make and attend appointments is not always appropriate and can significantly impinge upon their right to confidentiality, especially when information about the patient is relayed to or even addressed directly at the person who is accompanying them.

## Impact on dignity and quality of life

Through our study, people reported that the difficulties of accessing services, and the lack of the correct support in place, can have a significant impact of that person's quality of life and wellbeing. From missed appointments to the wrong use of medication, to a delay in getting sight impairment certification and therefore registration. The fact that sometimes people had to chase for follow-up appointments or support/equipment was frustrating and often detrimental to their wellbeing and dignity. What's more, not everyone was in a position to do so themselves, or had someone who was willing/able to do it for them.

The implications of this were much wider. Not being able to participate in family life, or continue doing the things they enjoyed, could lead to increased isolation and vulnerability.

**'With my grandchildren, I have to make up what they're saying because I don't like to keep saying 'I can't hear you!'**

**Participant with age-related hearing loss**

There was an overwhelming consensus that people with a sensory impairment appreciated effective communication with professionals, and also between professionals in different departments and services. Having to repeat their story over and over again was not productive, and could be avoided by appropriate data sharing. Participants didn't want to consistently draw attention to themselves and felt that their impairment and needs should be recorded appropriately and flagged up.

**'The receptionist says 'go and take a seat over there!'**

**Blind participant**

It was generally acknowledged that there seemed to be a lack of awareness of sensory impairments by health and care professionals, particularly GP receptionists and care workers. Participants also recognised that these staff members often had very busy roles and, on the whole, were very good at their jobs.

Participants reported that they were not at all offended if they were asked if they needed assistance and in most cases welcomed it. Taking the time to acknowledge and accommodate any sensory impairment made a world of difference to that individual's experience. This also applied to staff who were able to be more flexible in the booking process.

# Recommendations

All the participants in this 555 project fully appreciated and valued the work that health and care professionals provide for them and were very aware of the pressures and time constraints imposed on them. However, this study highlights the importance of the need for appropriate support and communication for people with a sensory impairment, so that they are able to access and use services effectively. By listening to the voices of this report, we hope that we can encourage changes that can make the experience better for people with a sensory impairment in the future.

Reflecting the findings of this report, we offer the following recommendations. They cover a range of possibilities, whether from individual practitioners making small changes to everyday practice, to organisations such as Clinical Commissioning Groups and providers of services making changes at a strategic level, to local charities, including Healthwatch Essex, making changes in how they provide information and work together in partnership.

## **Adopt a more flexible approach to booking appointments for people with sensory impairments**

- We recommend that service providers, in particular GP surgeries, adopt a more flexible approach for patients with a sensory impairment. This includes the provision of alternatives to telephone or online booking systems, and also giving patients the option of a double appointment, which will help to accommodate their communication needs.

## **Better record keeping, communication and sharing of information between services**

- To adhere to the AIS, all service providers should be asking their patients about their communication needs and this should be recorded prominently on their patient records.
- A joined-up experience should be provided to patients by sharing communication and access needs information with other health and care professionals.
- All communication with the patient should be in their preferred format which will reduce missed appointments and ensure that patients are fully informed about their care/medication etc. It will also help to avoid any confidentiality issues.

## **Improved accessibility for sensory impaired people**

- Ensuring that Sighted Guides, Communicator Guides and appropriate communication support such as BSL interpreters is in place for patients, and then letting them know that this service has been booked for their peace of mind.
- Speaking clearly and asking if patients need assistance in finding a seat or getting to the consulting room, and alerting them as to when it's their turn.
- Being prepared to change consulting rooms to accommodate someone who has a sensory impairment, or who has particular needs (eg to bring a guide dog with them).
- Including more visual prompts in waiting rooms and making sure signage is clear and appropriate.
- Dentists removing their face masks, or using a clear one, for those who are hard of hearing or lipread.

## **Provision of sensory impairment awareness training to staff and review on regular basis**

- We recommend that frontline staff are given sensory impairment awareness training, and that this is reviewed on a regular basis.
- This should include understanding how services, such as BSL interpreters, are arranged, who's responsibility it is, and how equipment works, such as a hearing loop.

## **Improvement to care pathways**

- Commissioners and service providers should develop and maintain pathways of care that take account of all sources of support for people with sensory impairments, including appropriate signposting to voluntary and community organisations (as well as statutory services).

## **Educating sensory impaired people about their rights**

- Healthwatch Essex recognises the great work that the charity sector does in supporting those with sensory impairments. We recommend that we work together to highlight the rights and entitlements of these people so that they are empowered to seek further information or assistance (and even to complain) when something is not satisfactory or their communication needs have not been met.

## **Include sensory impairment access standards in service contracts**

- Commissioners should take into account access to services for sensory impaired people, when tendering or reviewing contracts.

## The Accessible Information Standard

It is without doubt that full adherence to the Accessible Information Standard by service providers will make a positive difference to patients with a sensory impairment.

For this to be successful, it is useful to think about how the AIS works and to plan for it in three stages:

### 1. Pre-appointment

- Can the patient access the letter/information and or make the appointment?
- Has communication or guiding support been booked?
- How will they get there?

### 2. Appointment

- Is the entrance and reception area accessible in terms of layout, loop system, and staffing?
- How will they be alerted that they are being called for their appointment?
- Can the patient get to the consultation room?
- Are they able to understand and fully engage with what they are being told or asked?
- Are the public areas including bathrooms fully accessible?
- Do all staff understand how best to support them?

### 3. Post-appointment

- How will the patient manage their prescription collection and access written medication instructions?
- Has the Certificate of Visual Impairment been completed and sent?
- Has information, advice and guidance been provided to further support – especially Rehabilitation, equipment and emotional support?

**There is plenty of guidance about the AIS on the NHS England website**

**<https://www.england.nhs.uk/ourwork/accessibleinfo/>**

# Our main findings

## Booking and attending appointments

### Difficulty in booking appointments

We asked participants how they went about accessing services. A significant majority had experienced, at some point or other (some on a regular basis), difficulty in making appointments, in particular with GP surgeries.

Participants who were Deaf or had a hearing impairment told us that they found it challenging using the telephone booking system operated in many GP surgeries. It was reported that some surgeries even operated a triage system where the patient is called back by the GP before being able to make an appointment. Many said that using the telephone is by far the worst experience for them and the Text Relay service was impractical to use because of being put on hold so often.

‘I would really like them to talk more slowly and clearly – there’s only so many times I can say pardon! I sometimes put the phone down and think ‘what did they say?’

Hearing impaired participant

Some participants said that their GP surgeries texted through a confirmation of the appointment which was very useful, and some were even sent a text reminder.

‘My GP is great because they text me the appointment. This is the only accessible information I’ve been given – they’ve never asked me.’

Blind participant

The practices that did offer an online booking system worked well for some participants who had a computer or another device, in particular for advance appointments, but many felt they were not so effective for same-day appointments. It was also apparent that although there were online booking options for some appointments, not all services provided this.

‘There is a facility for booking one appointment with a doctor online but no facility for making appointments for blood tests. I have a blood test almost every fortnight and ringing to make the appointment is a nightmare as I cannot always hear on the phone. Staff are great but still the hearing loss makes life difficult.’

Severely hearing impaired participant

Participants valued consistency and being able to see the same doctor or other professional so that they didn't have to repeat their story each time.

## **Flexibility of appointments**

For many, the inflexibility of booking systems made life somewhat difficult and stressful. Whilst some surgeries did offer participants with a hearing impairment a double appointment which allowed additional time for communication, other participants commented on the lack of flexibility with their GP surgery's policy of on-the-day only appointments. It made it difficult for them to find a carer or family member to take them in time.

In some cases, due to the difficulties they faced in booking an appointment, participants simply don't go to the GP when they perhaps needed to.

**'It's hopeless, I don't go to the doctors. I am unable to get myself up before 8.00am. I need someone with me.'**

**Deafblind participant**

One profoundly deafened mother said that her GP refuses to give her appointments in advance. She has been told that she either has to call in the morning, or go in very early and queue.

**'I have not made appointments for months sometimes, due to this problem. When I asked at reception "how do deaf people make appointments then?" her reply was to shrug her shoulders and say: "we've never had a complaint before.'**

**Profoundly deafened participant**

In fact, several participants reported that they felt forced to book an appointment in person, as they were unable to use or see the phone and had to attempt to 'beat the masses' and queue up outside before the surgery opened. This proved difficult in many cases, particularly for people who lived in rural areas, as bus services didn't start early enough to enable to arrive at the surgery in time.

## Reliance on friend / relative / carer

Many participants relied on a family member or carer to make appointments for them, which they felt was not only an inconvenience for that person, but also in some cases, inappropriate and compromised their patient confidentiality. Several participants had been asked by receptionists if there was anyone else who could phone to make the appointment for them.

‘I shouldn’t have to depend and rely on my husband. It seems, that it’s confidential information – I’m going to make the appointment myself, it’s my information and they should reply and respond to me!’

Profoundly deaf participant

Another participant from Chelmsford needed his wife to make appointments at 8.30am, which was not always convenient due to work commitments.

‘If I didn’t have her then I think I would really struggle to get at the front of the queue if I needed an emergency appointment (or I needed one for my children).’

Hearing impaired participant

Those who relied on a BSL interpreter encountered a similar problem with the lack of flexibility in the booking process.

‘I have to wait for an interpreter to be able to phone the GP. I can only do when interpreter starts at 10.00. Then all the appointments are full for that day!’

Deaf participant

A Deaf man from Chelmsford had asked his GP surgery if he could email for an appointment.

‘They said, no you need to ask a family member or friend to assist you. I’m not happy with that. Where is my accessibility? It’s very hard.’

Deaf participant

## Technology used in waiting rooms

Checking in at a GP surgery was also not without problems for sensory impaired people. Once again there was a reliance on having someone with them to be able to cope with the technology used at the surgery or clinic.

‘I struggle with the automatic booking in screen - it keeps rejecting me and then there’s a long queue at reception. Sometimes you feel that your disability is not being taken on board.’

Visually impaired participant

Once in the waiting area, participants reported that there were either screens with the names of the next patient, or a tannoy system, but rarely both. Whilst some participants reported that they found the screens really useful because they are visual and could see when and which room to go to, for others with sight impairments this was not effective.

‘The screen bleeps, but I can’t see it.’

Blind participant

Many participants reported that they were afraid of not hearing their name being called and spent the whole time waiting in a state of heightened anxiety. Some found the scrolling announcements very helpful but others felt that they had to constantly watch it and daren’t look away. In many cases, participants were not made aware by reception staff if their name had flashed up or been called out, and had even missed their slot to be seen. It is evident that there is a need for a more flexible approach for hearing and sight impaired patients, in terms of alerting them to when it’s their turn to be seen.

‘It would just be nice if receptionist would come and get me.’

Participant with hearing loss

Others reported that their GPs and dentists were fantastic and came out of their rooms to greet them.

Participants told us that attending appointments, whether at the doctors, dentists or outpatients presented a range of issues and barriers. Many stated that they became anxious when they got to the waiting room.

‘When you’re ill, you don’t want to have to worry about being able to hear as well.’

Severely hearing impaired participant

Interestingly, participant’s experiences of dental practices were generally good and some reported that their dentist was even prepared to change surgeries to accommodate them. However, it was often the case that the surgeries were located up steep narrow stairs which proved a problem to those with sight impairments.

‘My dentist is upstairs – I’m prepared to walk up there as I like the dentist. The only problem is that rail is on the wrong side when I walk down the stairs – I would prefer there to be one on both sides.’

Deafblind participant

One thing that was mentioned was the fact that dentists often wore masks which presented a barrier for hearing impaired people and lipreaders, resulting in patients not understanding or missing what was being said. Some participants reported that they had chosen to seek private care, as they felt better looked after in terms of their impairment. One participant reported that, at the private practice she visited, the dentist wore a clear face mask and had pictures of the treatments, which really helped and made her feel reassured.

## **Staff awareness**

However, concerns were raised about the lack of awareness of sensory impairment from reception staff, in particular at GP surgeries, and the fact that it appeared that there was no note of the impairment on their records. Because of this, participants were not often asked if they needed assistance.

‘They think that because you’ve walked through the door (even if you’ve fallen over a chair in the process) you can manage.’

Severely visually impaired participant



According to participants, the levels of awareness amongst surgeries varied greatly. Some were very aware and helpful (mostly for the participants that had been registered at the surgery for a very long time and saw the same doctor) and others not so. One Deaf lady had even moved to another surgery much further away simply because of their lack of awareness and support. Some reported that staff seemed unaware of what a red and white cane was for.

‘One member of staff asked me if the red bit on my cane was because I’m partially sighted. I said no, it’s because I’m deaf as well!’

Deafblind participant

A few of the participants told us that their surgery did not have a hearing loop (or at least there was no indication of there being one in place) or, if they did, staff didn’t understand how it worked. It was considered important that staff understood the difference between hard of hearing and profoundly Deaf, and also knew how any equipment worked.

Many people felt embarrassed to talk about their impairment in a public place and draw attention to themselves. Participants therefore valued staff talking clearly at all times.

‘If I want to discuss something private at reception, there is no privacy. In order for me to hear, half of the waiting room will hear too!’

Hearing impaired participant

For lipreaders, it was important that receptionists looked up and spoke directly at them. This also applied to GPs who had a habit of facing their computer screens and typing during appointments. There was also great difficulty with professionals who had an accent. In fact, some participants with hearing impairments reported that they would usually have to bring someone with them, or ask the professional to write down what was being discussed.

‘What’s so important is that I need to know what they are talking about, if I don’t understand, I do resort to asking if I can see their computer.’

Deaf participant

## Case study

Deborah from Braintree who is Deafblind and was born with Usher Syndrome, also has Meniere's disease, which causes vertigo and nausea. Deborah has been put off from using her GP after a bad experience last year.

She was suffering from a particularly bad episode and her communicator guide, who had already been booked for that day, insisted she made an appointment and take her to the doctors.

Upon arrival at the surgery, there was a long queue and they were told to use the touch screen to book in. This is a problem for Deborah and the screen wasn't working properly and so, as she was feeling unwell, she sat down, with her guide dog, while her communicator guide returned to the queue. "I was then approached by a member of staff and asked why I wasn't using the booking in screen!".

After a while she was sent upstairs to a consulting room. "The lift was dark so it was fortunate that my communicator guide was with me!". The Receptionist upstairs informed Deborah that she would not be able to take the dog into the surgery as the GP that was usually based in that room was allergic to dogs, and would her 'friend' be able to look after it. "I was quite upset – this is not my friend, this is my communicator guide and I need her with me to assist with communication".

Her communicator guide asked if the Receptionist would look after the dog in this instance, but they said that they couldn't, and so she then asked if it was possible for the doctor to move into another room. The doctor did agree to this. "Once I was seen, it was marvellous. But I haven't been back since as the service is so inconsistent, it has put me off. Making and attending appointments and accommodating an individual's needs is a real barrier to someone with impairment".

## Case study

Sarah has a bi-lateral hearing loss, brought about by Meniere's disease. It came out of the blue when she was in her late twenties and happened very gradually. In the early stages of its progression it was particularly aggressive and difficult for her to manage. Out of all the symptoms, the hearing loss has been the most difficult to come to terms with. She now wears two hearing aids, which are 'T' switch enabled, which means she can use a hearing loop system in public places that have this facility.

It used to be the case at the GP Surgery she goes to that the first encounter at the reception desk could prove difficult. Hearing loss, in many cases, is an invisible disability and it is not always evident to people that you may have a difficulty with communication. "Receptionists with quiet voices, or people who speak too fast or type on computers whilst they are talking to you, means I can't lipread them". This has meant that in the past Sarah hasn't necessarily got the information she needed.

At her GP surgery, Sarah used to worry about hearing her name being called out. "I've lost count of how many times I've found myself going back to the desk to double check that I have not missed my appointment call. It's hard when your name is called through a speaker system by the Doctor".

A tactic Sarah employed to counteract this was to tell the Receptionist at the outset that they must get someone to come and get her when it was her turn to be seen. "This is really not satisfactory, because as anyone with a hearing loss will tell you, that drawing attention to yourself this way is hugely annoying, and it can make you feel marginalised."

Now things are getting better in her own GP surgery. They have adopted technology where a large screen actually displays the patient's name. "For people with hearing loss, that really is a godsend and you could say it is much more 'hearing loss friendly'".

# Visiting or staying in hospital

We asked the participants about their experience of hospitals.

It is often the case that patients receive a letter from the hospital and are then asked to telephone to arrange a date for the appointment. This proves particularly difficult for hearing impaired or Deaf people.

‘When I receive a letter from the hospital...it says I have to telephone to make a date. I go to pieces on the phone. So I would prefer email – it’s more accessible and another way for me to communicate and book an appointment.’

Profoundly deaf participant

Many participants agreed that it would be better if, during their hospital appointment, they were able to book their follow-up one at that time, as this would save a lot of stress and worry.

There was also some inconsistency in terms of accessing support required for appointments and whose responsibility it was to book it. Many participants spoke about the difficulty that they had experienced in booking interpreters or guides for their appointments, and how they had to ‘jump through so many hoops’ to get one in place. Some hospitals did not seem to acknowledge that Deaf and deafblind people had a right to an interpreter or communicator guide and that the hospital was responsible for booking that service.

‘I was booking an appointment in the haematology department and needed a guide. I was told it was ‘nothing to do with hearing or sight loss, so why do you need a communicator guide?’

Deafblind participant

Another participant spoke of the time she went to hospital and had asked for an interpreter to be booked, which, unfortunately, it hadn’t. She arrived and the doctor started talking straight away but wasn’t looking directly at her.

‘I could not understand and said ‘you can’t just talk at me, I can’t understand. I need an interpreter’ – it’s infuriating!’

Deaf participant

Another participant reported that it was quite worrying when she receives her confirmation letter about the appointment which doesn't make it clear that an interpreter has been booked.

'I would like it to confirm it for peace of mind. When I'm booking something, I just want it to be smooth.'

Profoundly deaf participant

## **Challenging hospital environment**

Participants spoke of how challenging the hospital environment was for them and had varying opinions on the signage used in hospitals. For the visually impaired it was important that clear signs were put at eye level and the right colour contrast was used as it could cause confusion unless they had someone with them. On the other hand, some of the hearing impaired participants found the screens to be really helpful.

'At hospitals I get worried about hearing my name. Making sure I hear and understand the doctor or consultant is also a problem.'

Hearing impaired participant

At outpatients, it was sometimes the case that nurses would come out into the busy waiting room and call out a patient's name. Participants reported that due to the busy environment, and the fact that they often sat at a distance, they could not always see who had called their name.

'I find that in hospital, staff haven't the time necessary to speak face to face with patients that have sensory loss, therefore it becomes a guessing game on what is being said.'

Severely hearing impaired participant

Participants found that access for guide or assistant dogs was inconsistent across different hospitals and this presented a barrier to them in terms of receiving the right care.

## Staff awareness

There were also varying opinions about the level of sensory impairment awareness amongst staff in hospitals.

‘At Broomfield (Hospital) there are many departments. When they discover I’m deaf they say ‘oh oh here’s the loop’ and I say, no, I’m profoundly deaf, it’s not going to work for me. You do get that response. It’s possibly an awareness issue.’

Profoundly deaf participant

‘I had a terrible experience. I appreciate the nurses are busy, but when they put medication on the table when I’m sleeping and don’t tell me! They also told me that the toilets were over there! Being blind, I couldn’t help myself or get someone.’

Blind participant

Several participants reported on the positive experience they had at Addenbrooks hospital, Ipswich Hospital and Moorfields Low Vision Clinic. Staff had an excellent understanding of sensory impairment, participants were able to see the same consultant and their records were clearly marked with their impairment and needs. Together this made visits run smoothly and participants felt more at ease.

‘Staff were absolutely fantastic – they put a sign over my bed using my words saying ‘I’m blind please introduce yourself’. Everyone spoke to me and told me what they were doing.’

Blind participant

However, one participant reported that she had been left in the toilet at one hospital for 20 minutes and was put in the furthest bed away.

‘I knew it was 15 steps away – other patients ended up helping me. There weren’t enough staff or they didn’t have enough time... When you’re deafblind, you can’t watch TV or pour yourself a drink – you rely on the staff to help.’

Deafblind participant

## Importance of volunteers at hospitals

The importance of volunteers at hospitals was flagged up several times during the focus groups, as was the role of Eye Clinic Liaison Officers (ECLOs) who work closely with the medical and nursing staff. Sometimes volunteers were available at hospitals to escort sensory impaired patients to the right part of the hospital – this was considered extremely valuable.

Many participants reported that once they had been given a diagnosis, or told that no further treatment would be effective, they were discharged and left with no support or counselling to deal with their sight loss. In some hospitals, charities supported ECLOs who were able to help patients find emotional support, information and advice for them and their families, and help to maintain their independence.

It was generally perceived that clinicians tended not to offer any signposting or advice on what people could do next to maintain their independence or deal with their sensory loss.

**‘That’s what happened to me the first time. At Romford hospital the doctor just said “this is your problem, nothing can be done” come back in 3 months’ time.’**

**Deafblind participant**

At hospitals, participants wanted information as soon as possible, so that they weren’t left in the dark or had to search for support themselves.

## Case study

Hannah, who was born partially deaf, suddenly lost her hearing before she left school. She classifies herself as 'stone deaf', is able to speak adequately, but not always able to understand what people are saying to her.

Last September, Hannah was in immense pain with her gall bladder and her son rushed her to hospital. Her son, who acted as interpreter, phoned ahead to advise them they were on their way in.

"I think I was there about midnight, they were very good. The doctor came and then we went into a cubicle and my son was able to give me snippets of what people were saying all around me. I couldn't hear anything, so he was trying to keep me informed".

There was a foreign nurse, but due to her accent, Hannah was unable to lipread her so she relied on her son. After some basic tests, she was told that she would have to stay and they found her a bed.

Shortly after, her son had to leave to go to work, which meant that Hannah was left without an interpreter. "I have to say, I think I was looked after well by this nurse. I had fallen asleep and she gave me a gentle tap and showed me that she was going to take my blood pressure"

Unfortunately, Hannah encountered problems understanding some of the other nurses and particularly the two doctors that treated her. "I couldn't understand a thing. I said to them, 'don't be frightened to write things down'. So off they went to get a bit of paper".

This helped significantly with the communication barriers, so for Hannah, it wasn't too much of a problem. In total, Hannah stayed in hospital for 4 nights and had no professional interpreter for her entire stay. "Obviously, it's not ideal, but I could read, so on the whole I was quite happy".

## Case study

Elizabeth was diagnosed with Retinitis Pigmentosa at Moorfield hospital in 2009. She had been discharged from Broomfield hospital as they couldn't find anything wrong. "I went through mainstream school and didn't really have a problem with my eyesight until they retained my driving licence five years ago. I had normal life up until then, but then it went downhill quite rapidly'.

She went to Broomfield Hospital for an appointment for her teeth. "I went to the new bit and didn't know my way around at all. Stupidly I didn't take anybody with me".

Elizabeth became really confused and ended up going back to main desk to ask for help. "There were big screens that I couldn't read properly – I still don't know what they were saying". She was advised to sit in the waiting area and wait for her name to come up and then follow the instructions to the room. "If you haven't got good sight, you cannot see what is on that board. You are put off from going to appointments from the stress and confusion. The more flustered I get, the less I can see."

## Social care and other services

Participants were asked about their experiences of using services provided by Essex County Council and other support providers.

### Importance of CVI and being registered

During the discussions, a lot of visually impaired participants remarked upon the importance of the Certificate of Visual Impairment (CVI). To be classified as sight impaired or severely sight impaired, an eye consultant needs to complete this certification form, and send a copy to the GP and to Essex County Council (ECC). ECC forward the certificate to ECL (Essex Cares Limited) Sensory service who make contact with the person to offer information advice, guidance and registration. This includes information on transport, equipment, rehabilitation training, emotional support, home visits, benefit entitlements, signposting to other support providers or referrals to the Low Vision Clinic.

Those who chose to be registered with the council may be able to then access a range of benefits or services such as a Blue Badge, TV license discount, some disability benefits / tax allowance benefit and some discounts on public transport such as a Disabled Person's Railcard.

Several participants commented on the fact that consultants seemed to lack understanding about the importance of this form to patients and what the emotional and psychological impact can be of it being delayed. Some participants even reported that their CVI had gone missing.

**'I was waiting for my CVI for ages – I had to chase and chase. It turned out that although the consultant had signed it, it had been filed away by the Secretary!'**

**Deafblind participant**

Losing their sight or hearing can have a significant effect on a patient's independence, and in turn their mental health. It was acknowledged that people can easily lose their confidence and it can take years to rebuild that, so it was paramount that they were referred or signposted to the right services and support right from the start.

## Charities and support organisations

Participants felt strongly about the need to have information and advice as soon as possible so that they could continue working and leading independent lives, as much as possible. They thought that GPs could take on the role of signposting patients to the relevant support groups and charities. The role of ECLOs was brought up again as an extremely valuable service to those with sight impairments.

A large number of participants commented on the fantastic support they received from charity and other support organisations.

‘My experience of social care has not been very nice, but they passed me on to ECL Sensory Service. They helped sort out my hearing aids and now the birds are singing again!’

Deafblind participant

## Social care services

Another participant remarked on her positive experience with her social care review and her social worker. They picked up very quickly about her psychological needs, and were going to write into the plan that she needs Cognitive Behavioural Therapy (CBT).

‘Thank goodness for social care – I can’t talk to the GP about it as they don’t understand!’

Deafblind participant

Unfortunately, some participants thought that the majority of care workers had very little awareness of sensory impairment and were unsure if they received any training on this. Some of these participants often preferred to use private care support instead.

‘It’s great finally meeting people you haven’t got to explain everything to. I feel supported, accepted, cared for.’

Deafblind participant with neurological condition

A deafblind participant was concerned about the length of time he’d had to wait to have his hours of support extended, even though the funding had been agreed some time ago. He was also alarmed by the fact that there were apparently very few deafblind qualified assessors in Essex.

## Hearing aids

For those with hearing loss, the provision and availability of batteries for hearing aids was also often a big concern. Many participants collected them from their local audiology department. Although they were also available at libraries and other places, there had recently been a spate of closures and changes to arrangements. It was reported that it really depended on where you lived as to how easy batteries were to obtain.

‘If my hearing aid doesn’t work – I go to Broomfield [Hospital] they go through whole rigmarole of doing a test again and I’m just asking for batteries.’

Deaf participant

As a trip to get batteries was often difficult, participants suggested that a larger supply could be issued each time to make life slightly easier.

‘I haven’t got time to go back every other week – can’t they just give me a bigger supply, it’s ridiculous!’

Hearing impaired participant

‘If something goes wrong with my hearing aids, I’ll be deaf. I’m severely sight impaired too. Some districts give you two pairs of hearing aids – I only get one – so I would be lost!’

Deafblind participant

Some participants, particularly those who lived in rural areas, had to buy a large stamp and send it off with their old batteries, in order to be posted back some new ones. This was both impractical and inconvenient to participants.

‘Without my hearing aids I wouldn’t be sitting here today – I’d be six feet under.’

Participant with hearing loss



# Information and communication

All participants of the focus groups and the online survey, were asked if they had heard of or knew about the Accessible Information Standard and if they currently received information in their preferred format.

## Awareness of the Accessible Information Standard

The 'Accessible Information Standard' – which has been created by NHS England and relates to NHS-funded services – directs and defines a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents, where those needs relate to a disability, impairment or sensory loss.

The Standard applies to service providers across the NHS and adult social care system, and effective implementation requires such organisations to make changes to policy, procedure, human behaviour and, where applicable, electronic systems.<sup>2</sup>

Out of **110 participants, only 16** said they were aware of the AIS, the majority of whom were affiliated to one of the partner organisations.

It was generally agreed that there needed to be a range of alternative communication methods offered by service providers, as everyone is an individual and has their own needs and preferences.

The preferred formats discussed were

- Large print (LP)
- Phone
- Text message
- Email (and, for the visually impaired, the subsequent use of a screen reader)
- Audio
- Signed video or physical interpreter

<sup>2</sup> Source: NHS England SCCI1605 Accessible Information: Specification

## Information in the preferred format

Only five participants could categorically say that they did receive information in their preferred format, and it was noted that utility companies, banks, Boots the Chemist and Specsavers were already quite well practised in providing information in LP when requested.

‘Some letters from the NHS – they will print at the bottom of a letter to ask whether you’d like it in larger print – but you can’t see it! It’s like saying, if you can’t hear, put your hand up!’

### Visually impaired participant

A few patients received text confirmations from their GP, which was standard practice at some surgeries. Other surgeries had been asked by participants if there was an option to change the font size on letters, but were told that it was a standard format that could not be altered.

It was reported by one participant that the audiology department at Colchester Hospital (CHUFT) now used email, which was really helpful, although another participant who used this service was unaware of this system.

‘What has worked well is being able to email the cochlear implant centre at Addenbrooks for appointments and questions, rather than telephone. However, they’re the only ones who offer this service and reply promptly, as far as I’m aware.’

### Profoundly deaf participant

Some people reported having requested information in their preferred format and receiving it once, but then further correspondence reverted back to the standard format.

## Record keeping and sharing

'You should have the information in a format you want. Having this information recorded on your notes and transferring this information wherever you get sent!'

### Participant with hearing loss

It was suggested by participants that their sensory impairment could be better recorded on their notes, in a prominent position so that it was obvious from the start, what their needs might be.

The AIS states that a sensory impaired service user's requirements (or those of their carer/parents) need to be identified, consistently and routinely recorded, flagged up (to prompt staff to take appropriate action), shared as part of the existing data-sharing processes and as a routine part of referral, discharge and handover processes, and lastly, and importantly, met. This means that steps need to be taken to ensure that the individual receives information in an accessible format and any communication support which they may need, is in place.

The correct or preferred format (such as large print) was also important for forms and information given out at appointments. One participant went to pay at the reception desk after her dental appointment and was given a form and asked to 'sign there'. It was in normal print and when she asked what she was signing, she was told 'don't worry, you're not signing off my mortgage!'

Another blind participant was asked to sign a form on a recent visit to her dentist and a few months later received a fine for £50 for claiming free dental treatment.

'Had I been asked, or thought to ask, I would not have signed the form.'

### Blind participant

## Knowing and understanding your rights

Through the discussions, it was considered essential to understand your rights in terms of what communication support you were entitled to and who is responsible for booking and paying for it.

By law, under the Equality Act 2010, all health and social care providers are required to make 'reasonable adjustments' to make sure that a disabled person can access and use the service as close as possible to the way a non-disabled person would.

This means that all GP and dental surgeries should aim to provide suitable access for patients with hearing, visual and mobility impairments, including those in wheelchairs, as well as older people and those with learning disabilities. In addition, they should provide suitable means of communication, so that it is easy for people to book appointments in the first place.

### **Case study**

Eight years ago Sophie who is severely hearing impaired, was pregnant with her daughter. “I was due to go for a scan and needed an interpreter, more for my husband than me as he is profoundly Deaf”.

As Sophie didn't know her rights at that time, the receptionist said that it was ok if her husband's mother interpreted for them. At the scan they were given some devastating news. Because her mother-in-law was emotionally involved, she wasn't as impartial as an actual interpreter would have been.

“She heard the news before we did and there was a lot of whispering going on with the doctors and we didn't know what was going on. This is a perfect example of why interpreters should be used and not family members!”

In one case, an interpreter had been requested for a hospital appointment, but there had been a mix up with the booking. In the end, hospital staff found a porter who was able to sign, but had a lower level of BSL than a professional interpreter.

**‘If we have an interpreter employed as a professional – we are all treated the same, we are then going to have the right communication accessible to us.’**

**Deaf participant**

## **Reliance on carers / relatives / friends**

Some sensory impaired participants relied on carers or family members to read correspondence and or communicate with health and care professionals on their behalf. This was not only inconvenient, and sometimes resulted in a delay in receiving the information, but also considered inappropriate due to confidentiality and risk of misinterpretation. The AIS emphasizes that this can seriously compromise the individual's right to privacy and that friends and family may not have the right knowledge and skill level to interpret the information, or are, in fact, not impartial.

'I receive information e.g. appointments etc. by letter but would prefer to receive everything by email so I could use a screen reader. That way all information would remain private to me unless I chose otherwise.'

Severely visually impaired participant

## **The implications of poor communication**

What came across during the focus groups was the need for health professionals to understand the implications that poor communication could have across the whole system or an individual's experience of care pathways. Conversations will not be effective if patients cannot hear and they will leave the appointment unclear of the next steps in terms of treatment and medication. There were implications for missing future appointments, or even mis-medicating for those with a sight impairment ,including where stickers were put over the top of braille, leading to future risks around people's health and wellbeing.

Communication needs to be a two way process, with a transmitter and receiver, otherwise it simply doesn't work. It was acknowledged that the basic lack of sensory awareness could have a significant detrimental impact on a patient's health.

One participant spoke of the time when her mother had a stroke last year.

'When they were questioning as to why she had a stroke – it was because she was taking her medication at the wrong time – she hadn't heard the instructions properly. This is a simple example of information that can obviously be confused. There was no actual label saying it would be morning or evening!'

Carer of elderly woman with a hearing loss

Another participant, who is 18 and profoundly deaf, had experienced a similar problem in hospital without an interpreter on hand.

‘When I was in hospital I was by myself, the next day my mum came and the doctor explained about taking the medication – I said I had already taken it so I was a bit panicky!’

Deaf participant

Upon learning about the AIS, there seemed to be discrepancy about whose responsibility it was to inform services about their needs. The general consensus was that it was up to the individual to alert staff as to their needs. Although this was not considered ideal, it was a step in the right direction towards getting their needs met.

## Case study

Bob was born with hearing loss and has Usher Syndrome. He had to give up work four years ago. Formerly, he was a postman and had a lot of independence. Since losing his sight, he went through the adult social care system, which was inappropriate, as the carers were unable to communicate effectively with him. Bob became very frustrated and angry. Six years ago, at a hospital appointment, Bob was told that nothing more could be done for him, he was signed off and no longer able to have eye tests or health checks. Despite the fact he can't see, he felt his eye health was still important.

With help from ECL Sensory Service, an appointment was made at Princess Alexandra Hospital for a check-up. This appointment was unfortunately cancelled three times. On the fourth time, he arrived at hospital, only to find that the appointment had been cancelled once again without any communication with either himself or his next of kin. Because there was no communication and they had arrived for the appointment, the hospital was charged for his communicator guides time.

Bob was referred for a bionic eye, but due to the fact that he had been effectively discharged and had missed any progress and update appointments, this was not able to happen. He currently receives 10 hours week of support which works well. He lives alone and his family struggle to communicate with him he has no other services coming in.

Bob always receives letters from service providers and has never been asked by anyone about his communication needs. He requires a Communicator Guide to attend appointments and uses block (letters written onto his hand) to receive all communication. It also appears that it is not on his medical records that he is profoundly deafblind and has communication needs.

## Case study

Yvette's sight went suddenly three years ago, after having dialysis. After a very long, painful experience, Yvette is now totally without sight and has one false eye.

Yvette is still adjusting to life without her sight, but does become frustrated with the lack of consistency and, in some cases, compassion when she attends appointments. A particular issue is the information, or lack of it, on her records.

Yvette would rather be asked about how she wishes to be classified and treated as an individual. "I wish that there wouldn't be so much political correctness. Some people say that I am severely sight impaired – I'm not, I'm blind. How much more blind can I be? I can take my eyes out!"

Another issue is having to repeat her story every time she sees a consultant or health professional. "If the information is marked properly on my notes, they won't assume I can just walk in and find a seat. It helps you maintain individuality". A particularly upsetting experience is that often when she goes for a consultation, the nurses undertake the same procedure of shining a light in her eyes and asking if she can see it. "Why do they do that every time? It's offensive and upsetting!"

On a recent visit to the nurse, Yvette was accompanied by a friend who waited for her in the waiting room. When the consultation with the nurse ended, she showed her to the door and then proceeded to explain what had been discussed and the next course of action with Yvette's friend, and not directly with Yvette herself. Yvette considered this to be a breach of confidence. "All she had to do was to ask me if I was ok with that or if I needed it emailed to me. Have I got 'idiot' written on my head?"

# Love Your Senses

## ‘Love Your Senses’ event 14th February 2017, Chelmsford

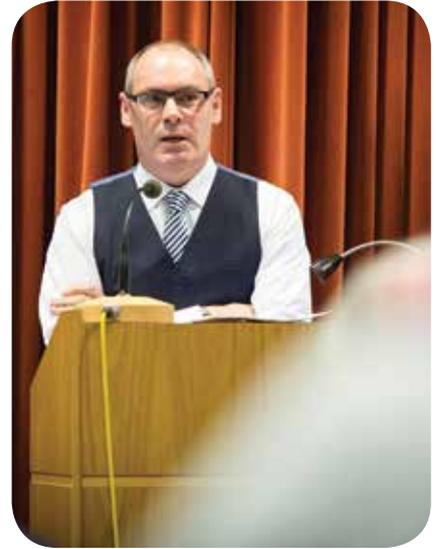
Heathwatch Essex hosted the 555 ‘Love your Senses’ event on 14th February 2017 in Chelmsford, Essex.

Leading up to the event, we held focus groups in partnership with ECL Sensory Service, the Royal Association for Deaf People, Support 4 Sight, Hearing Help Essex, and Essex Sight, to capture the lived experience of people who are visually impaired, hearing impaired, Deaf or deafblind.

They told us about their experiences of accessing and using health and care services in Essex.

At the ‘Love your Senses’ event, we gave five of these people the opportunity to share their stories, face-to-face, with professionals who deliver care throughout the county and beyond.





Representatives from all five Clinical Commissioning Groups in Essex, Essex County Council, two acute hospitals and both mental health trusts (SEPT and NEP) attended the event, along with others from local and London Borough councils and support organisations.

We asked these representatives to take the time to reflect and learn from the kind of insight that can only be gained through understanding people's lived experience. We hope that they can take on board suggestions about both what is working well and where improvements could be made.



**At the end of the event, we asked the audience for their comments and feedback:**

Staff at GP surgeries and hospitals do need training on sensory impairment and how to talk to us.

The sensory impaired world are delighted to find out about the Accessible Information Standard.

Please be aware that people who use BSL Interpreters may not have English as their first language. This group needs to be considered and the hospitals, NHS etc should provide the services needed i.e signer, interpreter, audio etc.

Regarding the AIS, what is the route for letting service providers know about our communication needs? Should it be via our GP?

Please talk to the person with the impairment and not the Communicator Guide or Interpreter.

Medication – it's important that we need to understand what it says and how to take it.

Fortunately, it's legislation now. The onus shouldn't be on us, but sadly in many cases it is. The AIS was communicated to all GP practices, but I have seen the flyer up on the notice board and still haven't been asked.

Communication must have a transmitter and receiver! If information has not been received and fed-back correctly, mistakes can happen.

The LD community also needs to be considered – Makaton, Easy Read or symbols.

Why are we behind Boots and Specsavers – they had this down ages ago!

We can get a good service – it's up to us to encourage it.

Where does the fine for non-compliance with AIS go? CQC issues the fines – but no one knows where the fine will go!

Use the complaints procedure - it's a positive thing as it has the ability to change policies.

## Conclusions – what should happen now?

Many of our findings are in keeping with national conversations about sensory impairment and accessing and using health and care services, such as the ‘Sick of It’ report (The Deaf Health Charity SignHealth).

What stands out from our study is that fact that everyone is different and needs to be treated as an individual. No two people living with the same impairment classification are the same, and participants would like service providers to recognise this. Records need to accurately reflect the person’s impairment and requirements, and be shared effectively amongst other service providers.

Often someone with a sensory impairment will also have another medical condition which needs to be treated/maintained, so to be made anxious, or put-off from making/attending appointments, or simply not understanding the information because of their sensory impairment, can have serious consequences to their health and wellbeing, not to mention a cost to the NHS or other care providers from missed appointments.

Having flexibility in the appointment booking process, and providing patients with information that they can access, is fundamental to them having a good experience. Participants valued kindness and manners – ‘a smile goes a long way!’

With an aging population, there are going to be more sensory impaired people, so it is important that effective systems are put in place now, to accommodate future demand.

We encourage health and social care commissioners, providers and frontline staff to recognise the findings of our study, and apply them to their role any way they can. Adhering fully to the NHS Accessible Information Standard will make a positive and welcomed difference to individuals with a sensory impairment.

We recognise this qualitative snapshot of people’s lived experience can only be the beginning of improving the way people with sensory impairments access and use health and care services.

We hope that this beginning will present a rich tapestry of voices - some positive, some negative, but all worth listening to if we are to truly deliver what patients living with a sensory impairment need in Essex.

## Glossary - definition

Term / abbreviation	What it stands for
<b>Accessible information</b>	Information which is able to be read or received and understood by the individual or group for which it is intended.
<b>Alternative format</b>	Information provided in an alternative to standard printed or handwritten English, for example large print, braille or email.
<b>Braille</b>	A tactile reading format used by people who are blind, deafblind or who have some visual loss. Readers use their fingers to 'read' or identify raised dots representing letters and numbers. Although originally intended (and still used) for the purpose of information being documented on paper, braille can now be used as a digital aid to conversation, with some smartphones offering braille displays. Refreshable braille displays for computers also enable braille users to read emails and documents.
<b>British Sign Language (BSL)</b>	BSL is a visual-gestural language that is the first or preferred language of many d/Deaf people and some deafblind people; it has its own grammar and principles, which differ from English.
<b>BSL interpreter</b>	A person skilled in interpreting between BSL and English. A type of communication support which may be needed by a person who is d/Deaf or deafblind.
<b>Communication support</b>	Support which is needed to enable effective, accurate dialogue between a professional and a service user to take place.
<b>Communication tool / communication aid</b>	A tool, device or document used to support effective communication with a disabled person. They may be generic or specific / bespoke to an individual. They often use symbols and / or pictures. They range from a simple paper chart to complex computer-aided or electronic devices.

Term / abbreviation	What it stands for
<b>d/Deaf</b>	A person who identifies as being deaf with a lowercase d is indicating that they have a significant hearing impairment. Many deaf people have lost their hearing later in life and as such may be able to speak and / or read English to the same extent as a hearing person. A person who identifies as being Deaf with an uppercase D is indicating that they are culturally Deaf and belong to the Deaf community. Most Deaf people are sign language users who have been deaf all of their lives. For most Deaf people, English is a second language and as such they may have a limited ability to read, write or speak English.
<b>Deafblind</b>	The Policy guidance <a href="#">Care and Support for Deafblind Children and Adults (Department of Health, 2014)</a> states that, “The generally accepted definition of Deafblindness is that persons are regarded as Deafblind “if their combined sight and hearing impairment causes difficulties with communication, access to information and mobility. This includes people with a progressive sight and hearing loss” ( <a href="#">Think Dual Sensory, Department of Health, 1995</a> ).”
<b>Disability</b>	The <a href="#">Equality Act 2010</a> defines disability as follows, “A person (P) has a disability if – (a) P has a physical or mental impairment, and (b) the impairment has a substantial and long-term adverse effect on P’s ability to carry out normal day-to-day activities.” This term also has an existing <a href="#">Data Dictionary definition</a> .
<b>Disabled people</b>	<a href="#">Article 1 of the United Nations Convention on the Rights of Persons with Disabilities</a> has the following definition, “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

Term / abbreviation	What it stands for
<b>Easy read</b>	Written information in an 'easy read' format in which straightforward words and phrases are used supported by pictures, diagrams, symbols and / or photographs to aid understanding and to illustrate the text.
<b>Impairment</b>	The <b>Equality and Human Rights Commission</b> defines impairment as, "A functional limitation which may lead to a person being defined as disabled..."
<b>Interpreter</b>	A person able to transfer meaning from one spoken or signed language into another signed or spoken language.
<b>Large print</b>	Printed information enlarged or otherwise reformatted to be provided in a larger font size. A form of accessible information or alternative format which may be needed by a person who is blind or has some visual loss. Different font sizes are needed by different people. Note it is the font or word size which needs to be larger and not the paper size.
<b>Learning disability</b>	This term has an existing <b>Data Dictionary definition</b> and is also defined by the Department of Health in <b>Valuing People (2001)</b> . People with learning disabilities have life-long development needs and have difficulty with certain cognitive skills, although this varies greatly among different individuals. Societal barriers continue to hinder the full and effective participation of people with learning disabilities on an equal basis with others.
<b>Lipreading</b>	A way of understanding or supporting understanding of speech by visually interpreting the lip and facial movements of the speaker. Lipreading is used by some people who are d/Deaf or have some hearing loss and by some deafblind people.

Term / abbreviation	What it stands for
<b>Speech-to-text-reporter (STTR)</b>	A STTR types a verbatim (word for word) account of what is being said and the information appears on screen in real time for users to read. A transcript may be available and typed text can also be presented in alternative formats. This is a type of communication support which may be needed by a person who is d/Deaf and able to read English.
<b>SNOMED CT (Systematised Nomenclature of Medicine Clinical Terms)</b>	Classification of medical terms and phrases, providing codes, terms, synonyms and definitions. SNOMED CT is managed and maintained internationally by the <b>International Health Terminology Standards Development Organisation (IHTSDO)</b> and in the <b>UK</b> by the <b>UK Terminology Centre (UKTC)</b> .  SNOMED CT has been adopted as the <b>standard clinical terminology for the NHS in England</b> .
<b>Text Relay</b>	Text Relay enables people with hearing loss or speech impairment to access the telephone network. A relay assistant acts as an intermediary to convert speech to text and vice versa. British Telecom (BT)'s ' <b>Next Generation Text</b> ' (NGT) <b>service</b> extends access to the Text Relay service from a wider range of devices including via smartphone, laptop, tablet or computer, as well as through the traditional textphone.
<b>Translator</b>	A person able to translate the written word into a different signed, spoken or written language. For example a sign language translator is able to translate written documents into sign language.

Source: NHS England, Accessible Information: Specification

## List of conditions linked to, or causing the sensory impairment of participants

Condition	Definition
<b>Retinitis Pigmentosa (RP)</b>	All types of Retinitis Pigmentosa affect the retina. RP causes the retinal cells to gradually stop working and eventually die. This affects your eye's ability to process light. (RNIB)
<b>Diabetic Retinopathy</b>	Diabetic retinopathy is a complication of diabetes, caused by high blood sugar levels damaging the back of the eye (retina). It can cause blindness if left undiagnosed and untreated. (NHS Choices)
<b>Diabetic Macular Oedema</b>	In diabetic macular oedema, blood vessels leak fluid into the retina. Vision loss occurs when the fluid reaches the macula (the centre of the retina that provides sharp vision) and builds up, causing swelling. At first, you may not notice changes to your vision. Over time, diabetic macular oedema can cause your central vision to become blurred. A healthy macula is essential for good vision. (Moorfields)
<b>Age-related Macular Degeneration (AMD)</b>	Age-related Macular Degeneration (AMD) is a painless eye condition that causes you to lose central vision, usually in both eyes. This sight loss usually happens gradually over time, although it can sometimes be rapid.  AMD doesn't affect your peripheral vision (side vision), which means it will not cause complete blindness. (NHS Choices)
<b>Glaucoma</b>	Glaucoma is an eye condition where the optic nerve, which connects your eye to your brain, becomes damaged. It can lead to loss of vision if not detected and treated early on. (NHS Choices)

Condition	Definition
<p><b>Marfan Syndrome</b></p>	<p>Marfan Syndrome is a disorder of the body’s connective tissues – a group of tissues that maintain the structure of the body and support internal organs and other tissues.</p> <p>Typical characteristics of Marfan syndrome include:</p> <ul style="list-style-type: none"> <li>• being tall</li> <li>• abnormally long and slender limbs, fingers, and toes</li> <li>• heart defects</li> <li>• lens dislocation – where the lens of the eye falls into an abnormal position</li> </ul> <p>(NHS Choices)</p>
<p><b>Cataracts</b></p>	<p>Cataracts occur when changes in the lens of the eye cause it to become less transparent.</p> <p>Cataracts sometimes start to develop in a person’s lens as they get older (age-related cataracts), stopping some of the light reaching the retina. This can affect your vision, making it become increasingly cloudy, blurry, or misty. (NHS Choices)</p>
<p><b>Charles Bonnet Syndrome</b></p>	<p>In Charles Bonnet Syndrome, a person whose vision has started to deteriorate sees things that aren’t real (hallucinations). (NHS Choices)</p>
<p><b>Dry Eye Syndrome</b></p>	<p>Dry Eye Syndrome, or dry eye disease, is a common condition that occurs when the eyes don’t make enough tears, or the tears evaporate too quickly.</p> <p>The symptoms of dry eye syndrome are mild for most people, although more severe cases can be painful and lead to complications. (NHS Choices)</p>

Condition	Definition
<b>Nystagmus</b>	Nystagmus is a condition which causes constant movement of the eyes which you can't control. It's caused by a problem with the way the eye sends messages back to the brain or how parts of the brain which deal with eye movement make sense of the information. (RNIB)
<b>Retinal detachment</b>	Retinal detachment occurs when the thin lining at the back of your eye called the retina begins to pull away from the blood vessels that supply it with oxygen and nutrients.  Without prompt treatment, it will lead to blindness in the affected eye. (NHS Choices)
<b>Hearing loss due to Meningitis</b>	Meningitis is an infection of the protective membranes that surround the brain and spinal cord. Meningitis can cause Sensorineural hearing loss, which occurs if the sensitive hair cells inside the cochlea are damaged, or as a result of damage to the auditory nerve (which transmits sound to the brain) (NHS Choices)
<b>Hearing loss due to German Measles</b>	Rubella (German Measles) is a viral infection that's now rare in the UK. Rubella usually only becomes a serious concern if a pregnant woman catches the infection during the first 20 weeks of her pregnancy. This is because the rubella virus can disrupt the development of the baby and cause a wide range of health problems, including: <ul style="list-style-type: none"> <li>• eye problems – such as cataracts (cloudy patches on the lens of the eye)</li> <li>• deafness</li> <li>• heart abnormalities</li> <li>• brain damage</li> </ul> (NHS Choices)

<b>Condition</b>	<b>Definition</b>
<b>Tinnitus</b>	Tinnitus is the term for hearing sounds that come from inside your body, rather than from an outside source. (NHS Choices)
<b>Hydrocephalus</b>	Hydrocephalus is a build-up of fluid on the brain. The excess fluid puts pressure on the brain, which can damage it. Visual impairment can be a long term complication of Hydrocephalus. (NHS Choices)
<b>Usher Syndrome</b>	Usher Syndrome is a genetic condition which affects vision, hearing and, in some cases, balance. (Sense)
<b>Ménière's Disease</b>	Ménière's Disease is a rare disorder that affects the inner ear. It can cause vertigo, tinnitus, hearing loss, and a feeling of pressure deep inside the ear.(NHS Choices)
<b>Ocular Albinism</b>	Albinism is the name given to a group of inherited conditions in which there is a lack of pigmentation (colour) in the eyes (Ocular Albinism) and often in the skin and hair as well. People with albinism find their greatest problems arise on sunny days and in brightly lit environments. Virtually everyone with albinism has Nystagmus. (RNIB)
<b>Auditory processing disorder</b>	Auditory Processing Disorder (APD) is a hearing or listening problem caused by the brain not processing sounds in the normal way.(NHS Choices)
<b>Dry Macular Degeneration</b>	Dry AMD develops when the cells of the macula become damaged by a build-up of deposits called drusen. It's the most common and least serious type of AMD, accounting for around 9 out of 10 cases.Vision loss is gradual, occurring over many years. However, an estimated 1 in 10 people with dry AMD go on to develop wet AMD. (NHS Choices)

Condition	Definition
<b>Wet Macular Degeneration</b>	Wet AMD – sometimes called Neovascular AMD – develops when abnormal blood vessels form underneath the macula and damage its cells. Wet AMD is more serious than dry AMD. Without treatment, vision can deteriorate within days. (NHS Choices)
<b>Myopia</b>	Short-sightedness, or Myopia, is a very common eye condition that causes distant objects to appear blurred, while close objects can be seen clearly. (NHS Choices)
<b>Optic Atrophy</b>	Optic Atrophy (also termed optic neuropathy) is the loss of some or all of the nerve fibres in the optic nerve. It is an important sign of advanced optic nerve disease and is frequently seen in visual loss. (www.patient.info)
<b>Otosclerosis</b>	<p>Otosclerosis is a condition in which there's abnormal bone growth inside the ear. It's a fairly common cause of hearing loss in young adults.</p> <p>In Otosclerosis, the stapes ("stirrup" bone) begins to fuse with the surrounding bone, eventually becoming fixed so it can't move. This means sound is no longer transmitted into the inner ear efficiently. (NHS Choices)</p>

# About Healthwatch Essex and the partners

## Healthwatch Essex

Healthwatch Essex is an independent voice for the people of Essex. We're here to understand the lived experiences of people who use health and social care services in the county and to make sure their voices are heard. We also provide an Information Service to help people access, understand, and navigate the health and social care system.

The Information Service can be contacted on **0300 500 1895**

**[www.healthwatchessex.org.uk](http://www.healthwatchessex.org.uk)**

## ECL Sensory Service

We are a team of sensory specialists delivering services across Essex and beyond. Our aim is to ensure that people can access the correct information, advice and support at the right time, in the right place and in the right way.

We achieve this by effectively working in partnership making the best use of local and national resources in order to deliver co-produced high quality services that are focused on prevention, early intervention and maximising independence. With a quarter of our sensory employees living with a sensory impairment, our services are unique in providing support that is shaped around individual needs focusing on improving the lives of our customers.

**[www.eclsensoryservice.org](http://www.eclsensoryservice.org)**

## The Royal Association for Deaf People (RAD)

The Royal Association for Deaf People (RAD) is committed to supporting Deaf culture, history and language. We consult with Deaf people to make sure we fully understand their needs.

We provide a wide range of services which Deaf people want and need. All of our services are delivered in British Sign Language (BSL). We also work with mainstream services to help them to ensure their services are accessible to Deaf people.

**[www.royaldeaf.org.uk](http://www.royaldeaf.org.uk)**

## **Support 4 Sight**

Support 4 Sight Essex assists people in maintaining their independence and quality of life. Our aim is to support local people throughout Essex to cope positively with their sight loss.

Our team also works to prevent avoidable sight loss and to raise awareness of the reality of living with sight difficulties.

[\*\*www.support4sight.org.uk\*\*](http://www.support4sight.org.uk)

## **Hearing Help Essex**

We work with those who have lived in the hearing world and who now find themselves with some degree of hearing loss, by offering practical help, support and guidance.

Our service is countywide. We also run Hearing Help Sessions in the following areas: Chelmsford, Maldon & District, Braintree & District and Uttlesford, where volunteers can clean and retube NHS hearing aids. Clients who live outside this area are welcome to visit us in the Resource Centre.

[\*\*www.hearinghelpessex.org.uk\*\*](http://www.hearinghelpessex.org.uk)

## **Essex Sight**

Essex Sight is the Community Services Division of Essex Blind Charity.

Essex Blind Charity has been caring for the blind and visually impaired of Essex since the 1920's. Our aim is to deliver a range of excellent support services to visually impaired people in Essex and the adjacent East London Boroughs.

[\*\*www.essexsight.org.uk\*\*](http://www.essexsight.org.uk)



## Find out more

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

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### Information Service

We can answer your  
questions about health  
and social care services

Call  
**0300 500 1895**

Monday to Friday 9am to 5pm  
for the cost of a local call

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