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South Glamorgan Community Health Council

# Sensory Loss Patient Experience When Accessing NHS Healthcare

15 December 2021



[www.southglamorganchc.wales](http://www.southglamorganchc.wales)

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You can download it from our website or ask for a copy by contacting our office.

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# About the Community Health Councils (CHCs)

CHCs are the independent watchdog of the National Health Service (NHS) within Wales. CHCs encourage and support people to have a voice in the design and delivery of NHS services.

CHCs work with the NHS, inspection and regulatory bodies. CHCs provide an important link between those who plan and deliver NHS services, those who inspect and regulate it and those who use it.

CHCs hear from the public in many different ways. Before the coronavirus pandemic, CHCs regularly visited NHS services to hear from people while they were receiving care and treatment. CHCs also heard from people at local community events, and through community representatives and groups.

Since the coronavirus pandemic, CHCs have focused on engaging with people in different ways.

This includes surveys, apps, videoconferencing and social media to hear from people directly about their views and experiences of NHS services as well as through community groups.

There are 7 CHCs in Wales. Each one represents the “patient and public” voice in a different part of Wales.

# Introduction & Background

The South Glamorgan Community Health Council strives to hear from patients and the public across all demographics, communities, and groups within Cardiff & the Vale of Glamorgan.

As well as requesting general feedback from the public on matters concerning their healthcare, the CHC also run specific, targeted campaigns for information and feedback from patients with specific health conditions or disabilities, or on specific services within the NHS, in order to ensure we hear from all groups of society with regards to their healthcare provision.

In this instance, the CHC wanted to hear directly from patients who suffer with sensory loss, about their experiences when accessing NHS Healthcare Services in Cardiff & Vale, with a view to making recommendations to Cardiff & Vale UHB on how to improve the experience from a patient point of view, if appropriate to do so.

# What we did

Due to the Covid-19 Pandemic restrictions, the South Glamorgan CHC has been unable to carry out physical scrutiny visits to NHS Services across Cardiff and the Vale of Glamorgan as we would under normal circumstances. As a result, we have been required to adapt the way we connect with patients and the public across Cardiff & Vale, in order to gather their views and experiences of accessing NHS Services.

The South Glamorgan CHC launched an online survey to gain feedback and insight from patients and the public who have sensory loss, across Cardiff & Vale, on their experiences when accessing NHS healthcare. The survey was listed on our website, and publicised through our Facebook and Twitter social media channels.

The survey ran from 1<sup>st</sup> March 2021 through to 7<sup>th</sup> June 2021, and asked questions around the following areas;

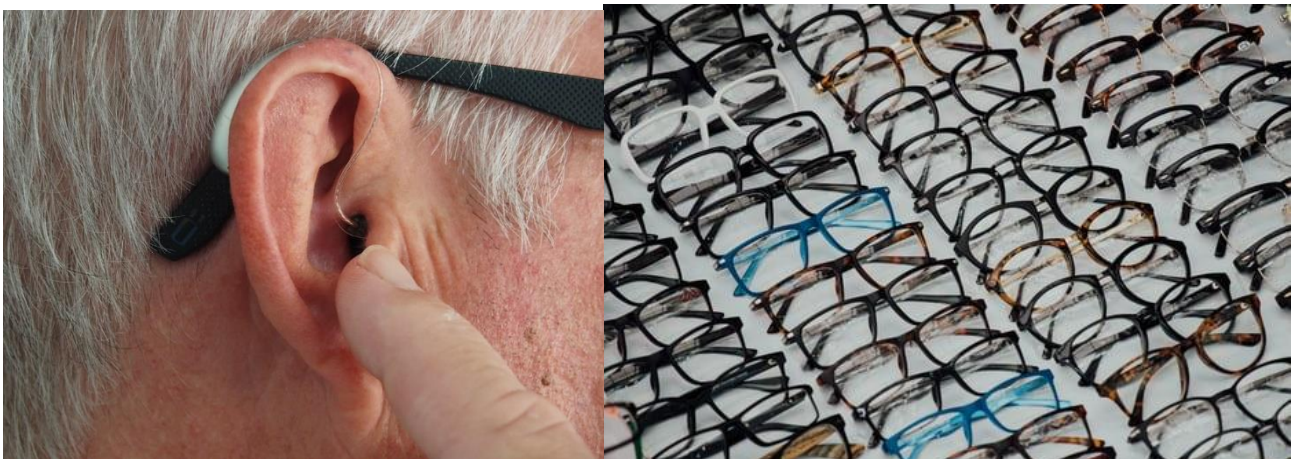
- Understanding a patients needs
- Access to services
- Experiences of those accessing services
- Suggested Improvements

# Who we are hearing from

**33** Respondents completed our survey.

Whilst this is a relatively low response to the survey, all feedback we received is welcomed and adds value to the work of the CHC. Through this report, the comments received were very powerful and clearly identified issues that need to be addressed.

Sensory Loss refers to the loss or impairment of one of the main five senses, most notably sight and hearing. There are many others conditions that may equate to sensory loss. We wanted to hear directly from these patients as they are more likely to find access to services differ compared to those with full sensory.



# What we heard

At a glance;

**14** (42.4%) people did not feel the NHS has a good understanding of their needs when accessing services.

**10** (30.3%) people agreed that the NHS has a good understanding of their needs when accessing services.

**9** (27.3%) people felt that the NHS only has a partial understanding of their needs when accessing services.

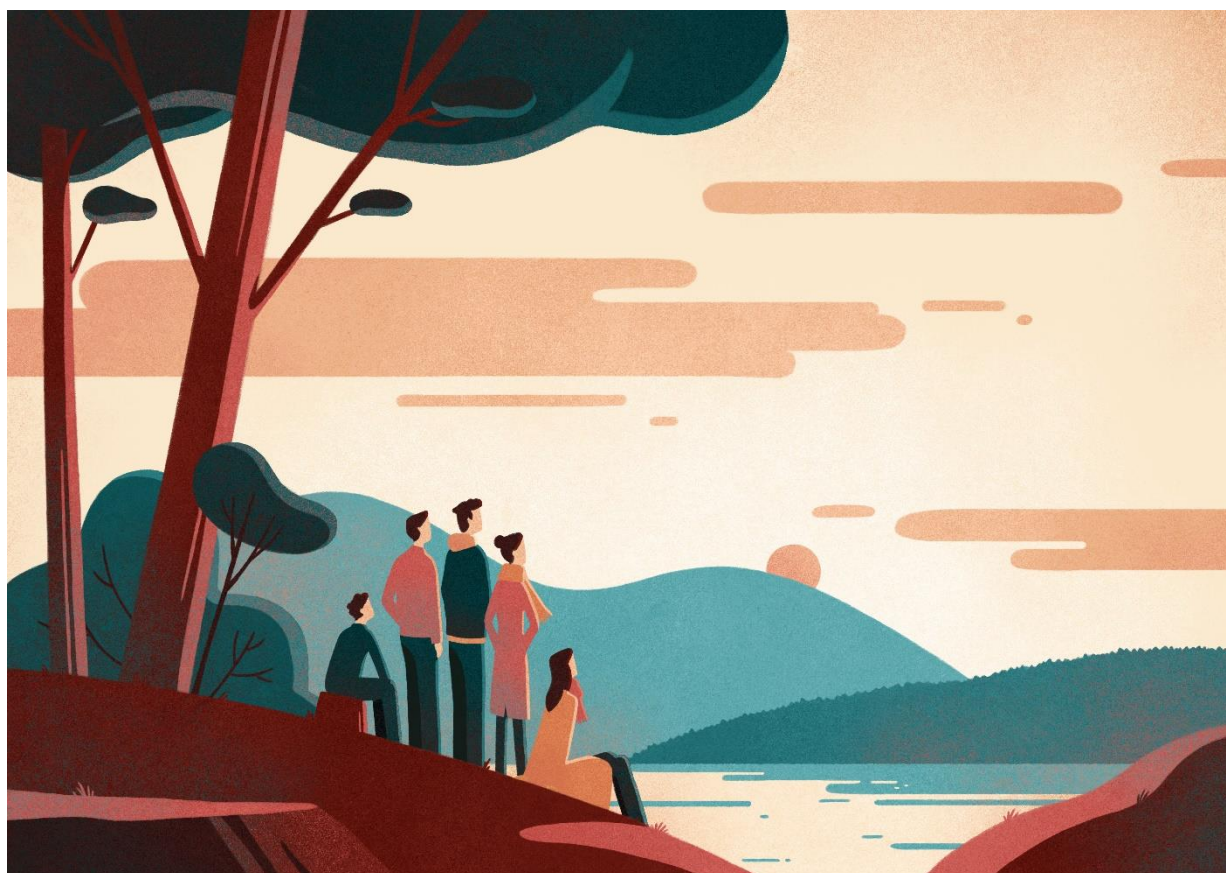


## **Access**

One of the main concerns the CHC wanted to look at was access, and to hear directly from patients with sensory loss within the Cardiff and the Vale of Glamorgan area about their experiences of accessing services.

The survey results have already highlighted that people think the NHS does not have a good understanding of their needs when accessing services. Whilst it is disappointing to hear, we need to understand what parts of the NHS and services are cause for concern.

Access can be split into two areas; physical access including the environment, and access to information through communication.



## Physical Access - environment

One patient explained they were unable to access services due to the location of the hospital.

*"I cannot access certain venues, such as Llandough Hospital, which relative to me are 'out in the sticks' and prohibitively expensive to taxi to/from. There are no easily accessible ways to claim back these excess costs"*

It would appear that areas of the NHS can be loud and unsuitable for some individuals. Some respondents explained the importance of quiet areas, or sensory rooms, for those with sensory loss.

*"There is no quiet areas for people who have sensory overload or autism or sensory impairments"*

*"Yes I would like to say that there is a quiet area in the clinic area and on the ward with sensory rooms and also for adults and children for both with autism and sensory processing and staff where Individual needs"*



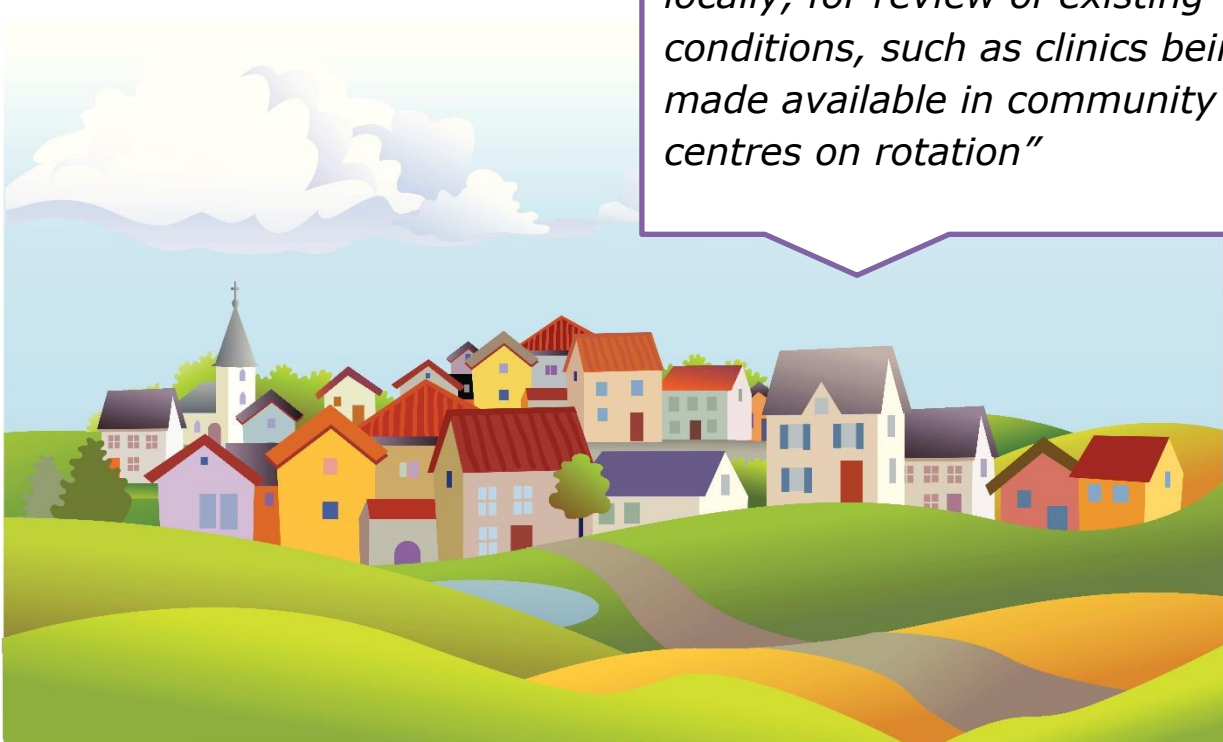
When asked how the services could improve access for those with sensory loss, one theme found was that people would prefer to access services in their local area.

*"More local clinics rather than the Heath."*

*"It would have been better to get a local face to face consultation rather than having to travel into Cardiff"*

*"A dedicated diabetes centre in every town, city and village in Wales. Proper care plans and access to tools to help manage Diabetes, for example blood monitoring devices that are capable of recoding information online giving access to a person's medical team. NiCE guidelines are not supportive and are only guidelines."*

*"More services to be provided locally, for review of existing conditions, such as clinics being made available in community centres on rotation"*



## Communication – Access to Information

As well as physical access, many respondents shared experiences of where communication has impacted their ability to access services. Communication is key, not only for people with sensory loss but for everyone trying to access services. Nevertheless, the UHB should ensure that those patients, particularly with sensory loss, can still access services and receive the correct information through communication methods which best suits their needs.

Positive experiences around interaction with staff were shared, including one positive experience where they had good communication.

*"On the whole they meet my needs"*

*"Always polite and helpful"*

*"I have been supported very well with the drop in device at the hospital."*

*"I am supported in a best way as I have sensory overload head and sensory processing and autism"*

*"As I found it difficult to accept my hearing loss, the gentleman who fitted my hearing aid at Barry hearing aid clinic was wonderful, explained everything clearly and made sure I understood. Excellent service."*

One respondent went further to say that the level of care was positive, however poor communication was a key concern for them.

*"The medical aspects of the service are very good – it's the lack of accessible communication and information that's lets you down."*

Respondents mentioned various types of written methods of communication, such as text, email, and letters. For example, one respondent praised the service for being able to communicate through email, however, as noted in another experiences not everyone can access technology.

*"When I've had issues I've managed to contact the NHS via email."*

*"Not everyone has access to the online service, I tried to sign up for it and was denied. I was told it was not in use in my area".*

*"No - appointment letters not accessible, appointments not accessible and I feel frustrated by this continuing inability to communicate with me in an accessible way."*

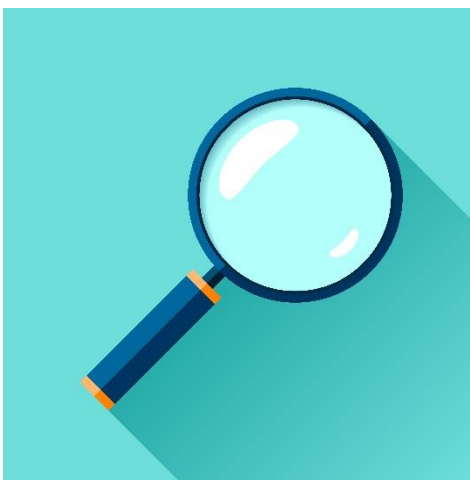
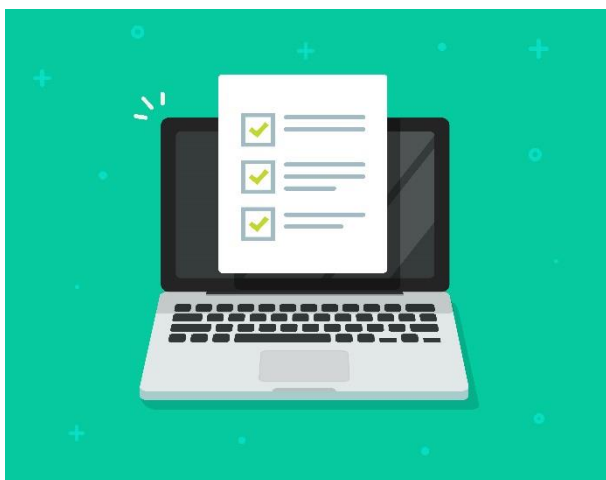


*"Despite years of campaigning and talking to health providers I still cannot get accessible appointments or information most of the time. This causes me to miss appointments and misunderstand information. Communication support is not provided for appointments which makes this stressful and full of communication issues."*

What may work for some may not be suitable for others, but it comes down to individual need and making sure there are different communication methods in place to allow patients to access services the best way for them.

When asked what could be improved, some respondents suggested making the text on letters bigger and clearer to ensure they can read the information received.

*"Yes would like appointments sent to me by accessible text message. Would like printed information to be large clear print. Would like communication support at appointments."*



Respondents also shared experiences where oral communication has been a concern. For example, some mentioned issues when waiting for their name to be called out in the waiting room, where they couldn't hear the intercom.

*"No consideration is given to patients with hearing loss. When attending appointments I become very anxious in case I miss my name being called out. I am also registered partially sighted, which makes getting around difficult."*

*"Yes there are difficulties, whether it's at the hospital or G.P.'s. For example when I attended my doctor's I informed the receptionist of my deafness and she said that she would listen out for my name being called and let me know. It didn't happen."*

And it's not just in the waiting room, but within the appointment itself, where it appears that more communication is required explaining and showing patients how to use certain devices.

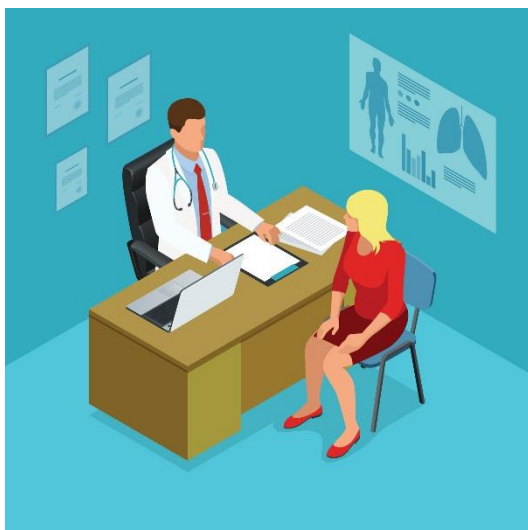
*"More time needs to be spent with patients during hearing aid fitting. Explaining/demonstrating the hearing aid features."*

It appears that respondents feel staff lack understanding of when it comes to patients and sensory loss, and they don't seem to adapt their communication (ie voice) to make it easier for the patient. It also seems they may not have full knowledge of some sensory loss procedures to know when there is an issue.

*"It's usually too much bother to deal politely with someone who has a hearing loss. So often, they'll mumble something under their breath (because I can't hear?), but I can lipread! Not a good way to deal with patients!"*

*"Am hard of hearing and have tinnitus. My dentist can't seem to understand that she can't talk to me with a mask on whilst using tools in my mouth and expect me to hear or answer her."*

*"I've had many conversations about T switches not turned on, not working etc. When talking on the phone, when I ask them to speak up as I can't hear, they'll say the next few words a bit louder then go back to the same as before. Very frustrating."*



*"I have a tracheostomy with speaking valve, which became blocked. The majority of staff have extremely rudimentary, basic tracheostomy Care Training, and this is very scary when you cannot breathe. Those who specialise in ENT, A&E or Critical Care are generally brilliant, but I had one unfortunate occurrence in A&E where I was moved to an area which couldn't allow deep suction due to Covid restrictions - this resulted in my tube very nearly becoming blocked once more. At this time I couldn't speak as had a cuffed tube in, and staff did not immediately understand the seriousness of the situation."*



## Seeing the right person at the right time

Finally, some patients felt they were unable to see the right healthcare professional to help with their health condition. As a result for one respondent, this meant they had a misdiagnosis.

*Ophthalmology Admin very courteous in numerous telephone calls but impossible to get clinicians to acknowledge that I exist!!"*

*"Now that I've finally got to meet the head ENT consultant and he suggested I had a CT scan, I have finally been diagnosed as what was causing my hearing loss, tinnitus and vertigo. Sadly the damage has been done now and is irreversible."*

When asked what could be done to improve access to services, it was suggested that staff needed to have a better understanding of individuals with sensory loss, to ensure their needs are met. It was felt this could be done through training.

*"Better time given to patients, more understanding."*

*"Routine training for all healthcare staff on ALL alternative airway management, including tracheostomies, laryngectomies."*

## **Appointments**

Respondents have told us they have difficulty in obtaining appointments since the start of the pandemic.

*"Once you get an appointment the service is great"*

*"Badly need my hearing aid looking at. Constantly giving off a high pitched sound which drives me mad. Badly need my feet done at a chiropodist."*

*"I've not had access to my usual services, I'm overdue for knee surgery I need access to sensory services and The Epilepsy Unit the rest can wait!"*

*"I can't get seen for hearing aid or feet at all."*

*"My appointments were cancelled"*

*"Very hard to get an appointment at hearing clinic. Doctors won't look at an infection unless ears are clear, wax removal won't happen when you have an infection. Catch 22"*

*"Before Covid, I had to wait 9 months to access an ENT consultant at The Heath hospital and nearly every time it was within a month of an appointment, it would get postponed, sometimes by a couple of weeks, Sometimes a couple of months."*

*"I have suffered a major problem with my ear for 66 years. Prior to Covid-19 I was treated every 6-8 weeks. Since Covid-19 I have only had 1 appointment and when I enquired about a resumption of treatment I was told I now need a new Dr. Referral even though previously I was told if it troubled my simply attend A& E no matter when! Privatisation through the back door!!!"*

## **Waiting Times**

Many respondents raised concerns around the waiting times to access services. One of the respondents even suggested that the UHB needed to keep patients updated to inform them of where they were on the waiting list.



*"ENT Clinic currently closed with over a year wait for hearing aid adjustments etc"*

*Waiting times need to be cut too. I used 2 private consultations in the past because I couldn't bear the wait."*

*"Keep people informed of the approximate time they will have to wait: can be done by email and reviewed automatically each month"*

# Learning from what we heard

Based on the findings of the survey, the CHC have identified the following opportunities for development;

- The majority of service users did not feel the NHS has a good understanding of their needs when accessing services; in particular around the environment and communication
- Individuals with sensory loss and/or sensory processing issues raised concerns over the lack of quiet areas, as loud and busy environments can be difficult for them.
- Service users would prefer to access services within their local area rather than going to the main hospital site, which at times can be difficult to access
- Communications are not always accessible, with concerns noted over appointment letters in particular. Specific mention was made of written methods of communication, which could be easily accessible if made large and clear to read.
- Staff need to be mindful when communicating with individuals with sensory loss, to ensure individuals can hear and understand what is being communicated to them.
- Staff should have a better level of knowledge and understanding of the particular service user needs.
- Service users are waiting a long time to get an appointment, and still struggling to get appointments.

# Thanks

We thank everyone who took the time to share their views and experiences with us about their health and care services and to share their ideas.

We hope the feedback people have taken time to share influences healthcare services to recognise and value what they do well – and take action where they need to as quickly as they can to make things better.

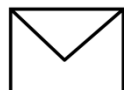
# Feedback

We'd love to hear what you think about this publication, and any suggestions about how we could have improved it, so we can use this to make our future work better.

This report is available in Welsh and English.



## Contact details



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If you write to us in Welsh, we will answer in Welsh. This will not lead to a delay in responding to your correspondence.

We welcome telephone calls in Welsh.

**South Glamorgan Community Health Council**