

IN THEIR OWN WORDS:

Insights and ideas from adult hearing service patients

RN | Supporting people
i:d | who are deaf, have
hearing loss or tinnitus

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EXECUTIVE SUMMARY

12 million adults in the UK are deaf, have hearing loss or tinnitus¹. This is 1 in 5 of us. By 2035, we estimate there'll be around 14.2 million adults with hearing loss across the UK¹.

With hearing loss being the largest potentially modifiable risk factor for dementia², the potential consequences of unaddressed hearing loss are considerable. Unaddressed hearing loss also increases the risk of social isolation, depression, and falls³.

Hearing devices, such as hearing aids and cochlear implants, are the only clinically effective treatment currently available for hearing loss. Despite hearing aids being free and available on the NHS, an estimated 5 million people in the UK who could benefit from them do not have them⁴.

Audiology services play a crucial role in providing support and treatments to improve people's hearing health. In recent years, audiology services have faced significant simultaneous challenges due to staff shortages and inadequate funding to meet demand. These challenges have been compounded by COVID-19 service disruptions and competing national health priorities. Worryingly, services have not yet returned to pre-pandemic levels of activity, meaning more and more people are waiting for an audiology appointment⁵. If urgent action is not taken, this number will continue to rise.

Given both the growing prevalence of hearing loss, and the high level of unmet

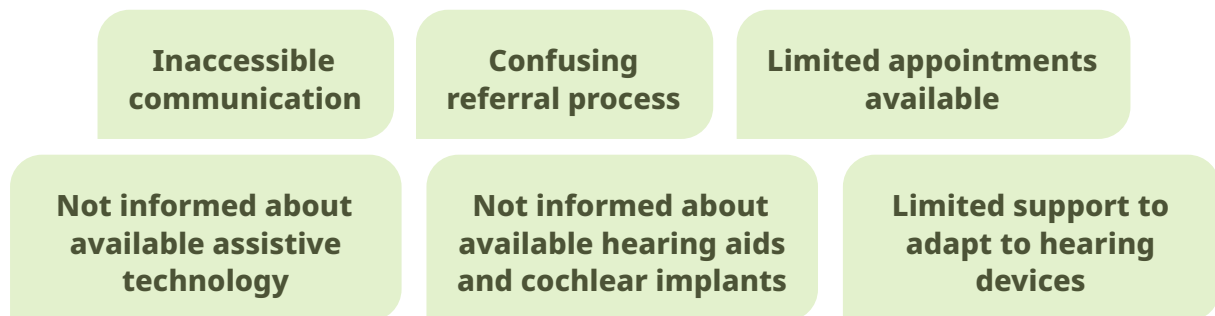
need, action is also needed to address future demand for adult hearing services.

As such, RNID believes the audiology pathway is ripe for innovation, to address the multiple challenges the system faces in a way that is more transformative and would create a system fit for the future. However, we also recognise that there is a significant opportunity for innovation and improvement within current audiology services.

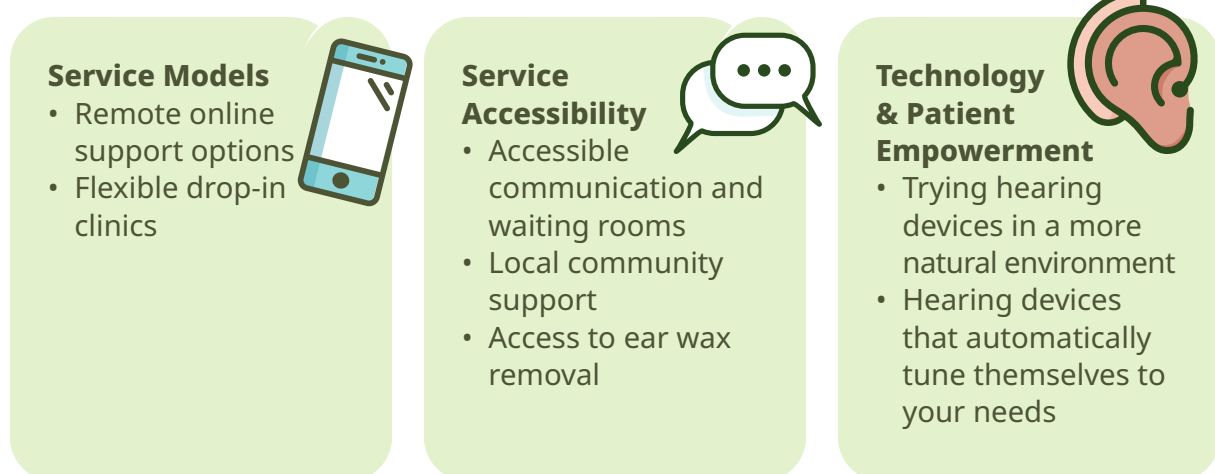
To help shape the conversation around adult hearing services RNID surveyed 1,204 people to understand their experiences so that improvements can be built on their needs.



Key challenges identified by adult hearing service users



Ideas for improvement by adult hearing service users



RNID is calling for:

1. Basic patient communication needs to be met. NHS and private healthcare providers must implement the relevant [accessible information standards](#)

2. Ear wax removal services meet population need. NHS commissioners should follow NICE guidelines to meet their populations' need. For a full set of recommendations, see our latest [ear wax report](#).

3. NHS healthcare providers to test replicating, and scaling existing solutions that address the opportunities for improving the adult hearing pathway. This includes improving service flexibility, the use of existing technology such as Bluetooth, and greater patient empowerment.

4. Greater investment in innovation for audiology. This includes funding to convene service providers and commissioners, technology innovators, patients, and academics; to trial and pilot new initiatives; and evaluate their impacts.



INTRODUCTION

12 million adults in the UK are deaf, have hearing loss or tinnitus¹. This is 1 in 5 of us. By 2035, we estimate there'll be around 14.2 million adults with hearing loss across the UK¹.

Hearing loss has been identified as the largest potentially modifiable risk factor for dementia², it is also associated with social isolation, depression, and falls³. Therefore, the potential socio-economic and health-related consequences of unaddressed hearing loss are considerable.

Hearing devices, such as hearing aids and cochlear implants, are the only clinically effective treatment currently available for hearing loss. Despite hearing aids being free and available on the NHS, an estimated 5 million people in the UK who could benefit from them do not have them⁴. The reasons for this are numerous, including lack of awareness and perceived stigma, but also, emerging difficulties accessing diagnosis and treatment within audiology.

Audiology services play a crucial role in providing support and treatments to improve people's hearing health. In recent years, audiology services have faced significant simultaneous challenges due to staff shortages and inadequate funding to meet demand. These challenges have been compounded by COVID-19 service disruptions and competing national health priorities.

Audiology services are still not performing the level of activity seen before the COVID-19 pandemic, and this has

ultimately resulted in a significant increase in the number of people waiting for appointments across the UK⁵. If urgent action is not taken, this number will continue to rise. Given both the growing prevalence of hearing loss, and the high level of unmet need, action is also needed to address future demand for adult hearing services.

As such, RNID sees the potential for innovation to be an essential part of this process. The use of technology to facilitate remote care and increase device uptake could provide immediate short-term improvement, while there is potential for greater transformation of services for the long term. However, it is currently unclear how our communities feel about current audiology services, and how they want to access audiology in the future.

RNID's ambition is to improve hearing outcomes for people experiencing hearing loss. RNID wants as many people as possible to have timely access to high quality hearing loss assessments, treatments, and support.

To help shape the conversation around adult hearing services RNID surveyed 1,204 people to understand their experiences so that improvements can be built on their needs.

METHOD

From July to September 2023, RNID ran an online survey to understand more about people's experiences of the adult hearing pathway and to explore potential areas for innovation.

The survey was shared through our Research Panel, RNID's newsletter, as well as via posters about the survey displayed in audiology departments.

A total of 1,435 people started the survey. A series of screening questions were used

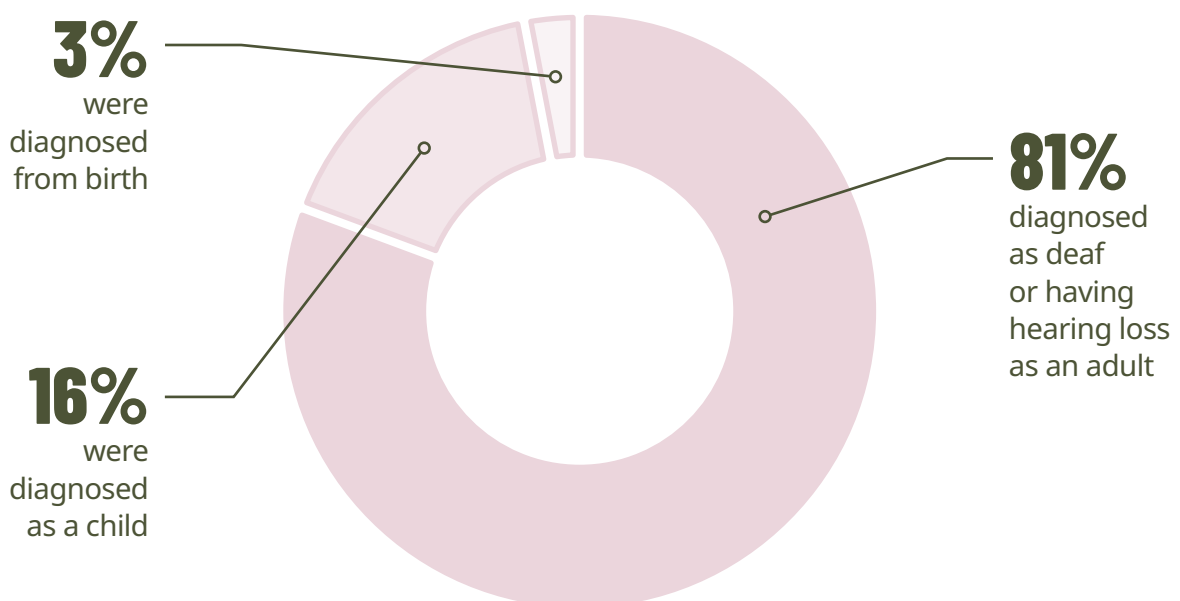
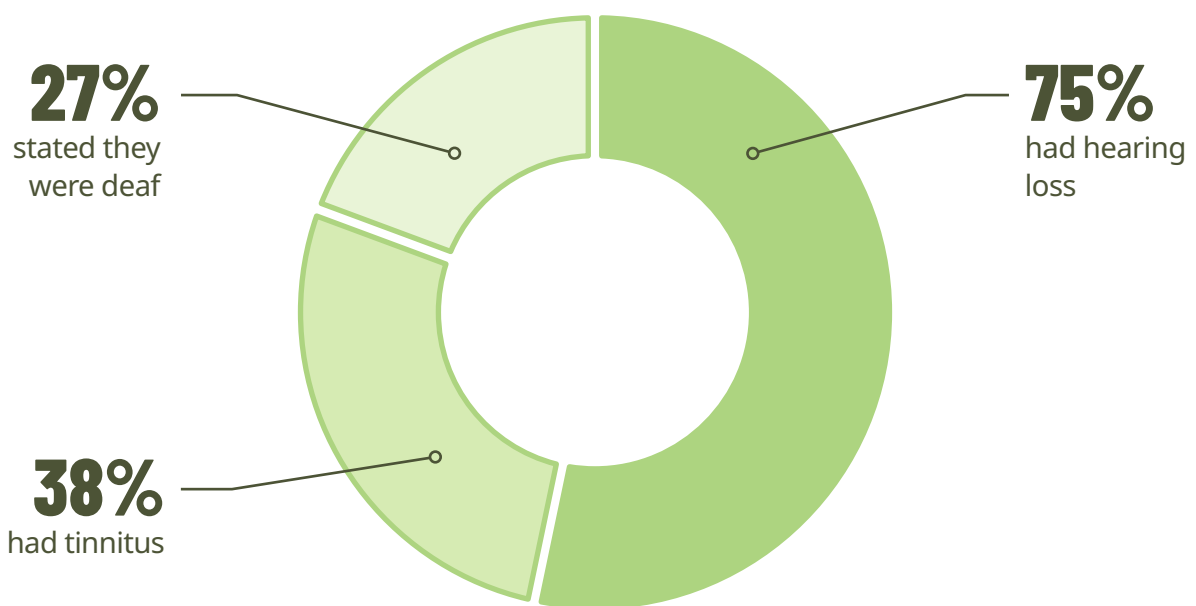
to ensure that only people currently using audiology services completed the survey. Those who had not accessed audiology services, or no longer use audiology services, were screened out. Anyone who had not yet been diagnosed with hearing loss was signposted to RNID's online hearing check where they could check their hearing for free.

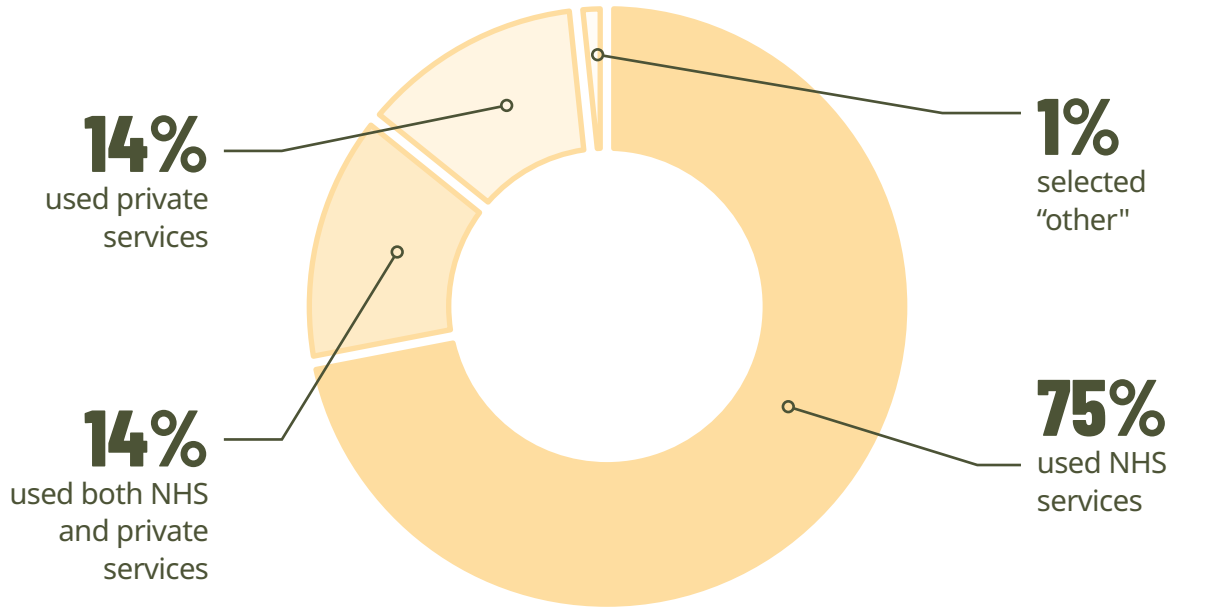
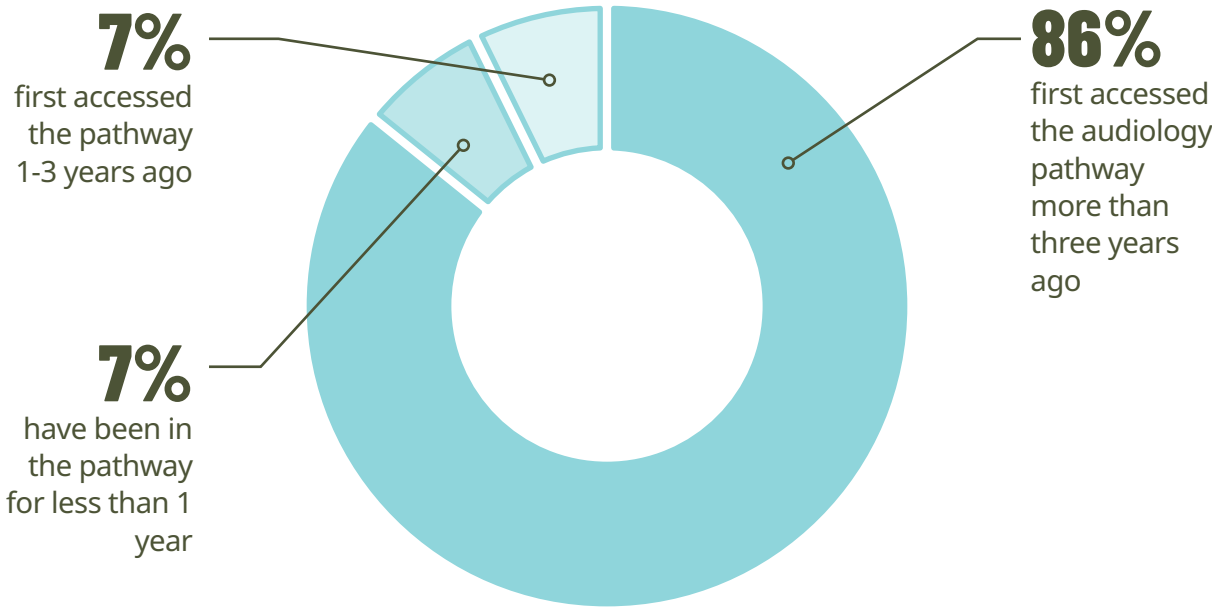
The following results are based on the responses of the remaining 1,204 people across the UK who completed the survey.



PROFILE OF SURVEY RESPONDENTS

People across the UK who are deaf, have hearing loss, or tinnitus, and currently accessing audiology services responded to the survey.





Respondents were often older, as over two-thirds (69%) were 65 years or above. However, this is not surprising given that the rates of hearing loss increase with age¹.

62% were women, meaning that women were over-represented in our sample.

There was also an under-representation of people from ethnic minority groups in our sample as 96% of respondents were White.

There was, however, a good geographic spread of respondents from across the UK.

EXPERIENCES OF DIAGNOSIS AND INITIAL FITTING

We asked the 14% of people who had been diagnosed relatively recently (in the last 3 years) about their experiences of the referral process, diagnosis, and having hearing devices fitted.

Referral to audiology

Over two thirds (68%) of people can get an initial referral to audiology easily. While this figure suggests the initial referral process is working for the majority, it does not include feedback from people who cannot access audiology services.

For those that find the process difficult, specific barriers include lack of appointments with both GPs and audiology services, and lack of knowledge about the referral process itself.

"I needed urgent support but was initially dismissed by my GP. Have continued to see private practitioner to get support whilst on the NHS waiting list."

User of both NHS and private audiology services

"When my hearing aids were fitted, no one explained how to get used to wearing them. When you don't know what you don't know then it is hard, and I think information could have been more proactively offered."

NHS audiology service user

Diagnosis

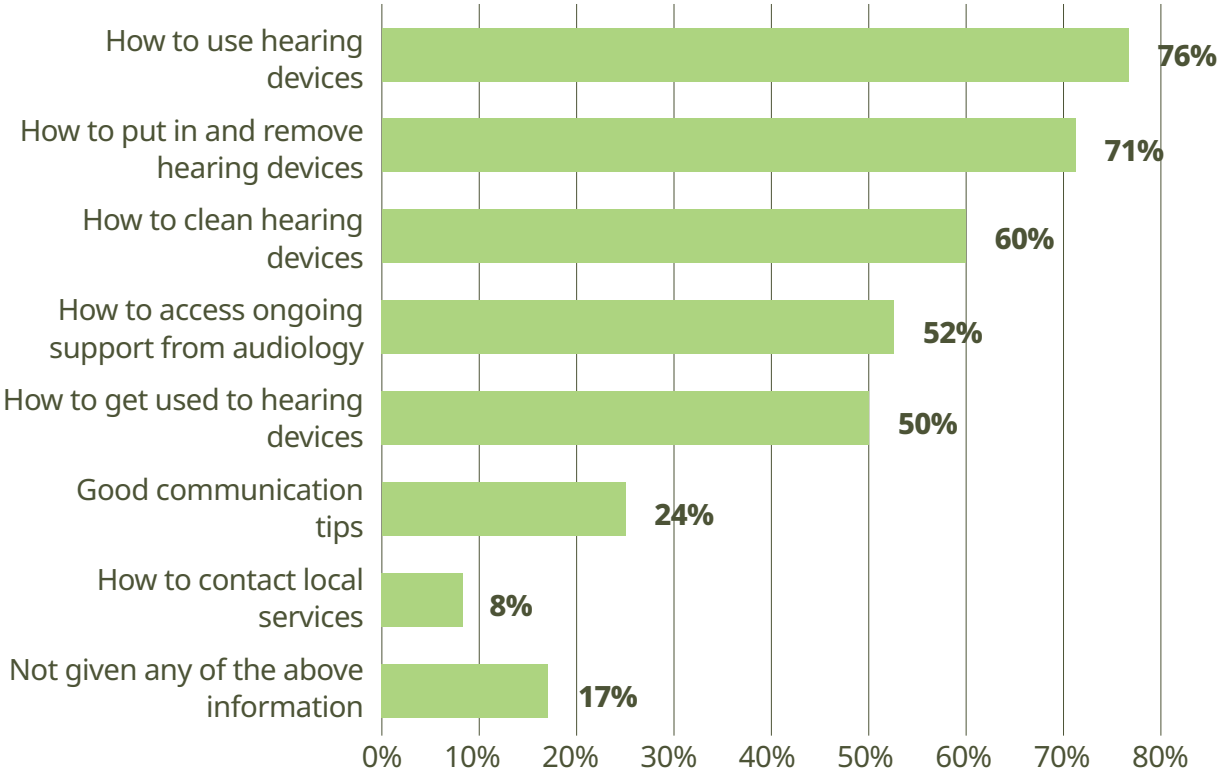
Some elements of the initial diagnosis process are working well. Most people agree the audiologist clearly explained the results of their hearing test (75%) and treatment options (72%).

However, while the majority (84%) agree they can ask questions in their appointments, only 64% feel they are able to make an informed choice about the best treatment option for them, and a similar number (65%) feel their chosen treatment option was a shared decision between themselves and the audiologist.

Initial hearing aid fitting

Once referred, the amount of information people recall being given in hearing aid fitting appointments varied considerably. While over three quarters recall information about how to use their hearing devices, only half recall being told how to access ongoing support from audiology. Worryingly, 17% say they don't recall being given any information.

FIGURE 1: Information recalled at device fitting appointment



This demonstrates clear gaps in information provision at initial device fitting appointments, where patients do not recall receiving the information and advice they need to help them adjust to their hearing aids and feel supported in the early stages of their hearing loss journey.

It appears that patients are receiving limited support in the early stages of their hearing loss journey, following initial diagnosis and fitting. Support in these early stages may be critical in helping patients not only adapt to their hearing devices but also to feel informed, supported and ultimately empowered to improve their health.

“Having hearing aids fitted for the first time was a big step for me and I did not feel there was time to talk about that. The process felt a little rushed and I was not quite the priority. Info was given quickly and I didn't quite absorb it.”

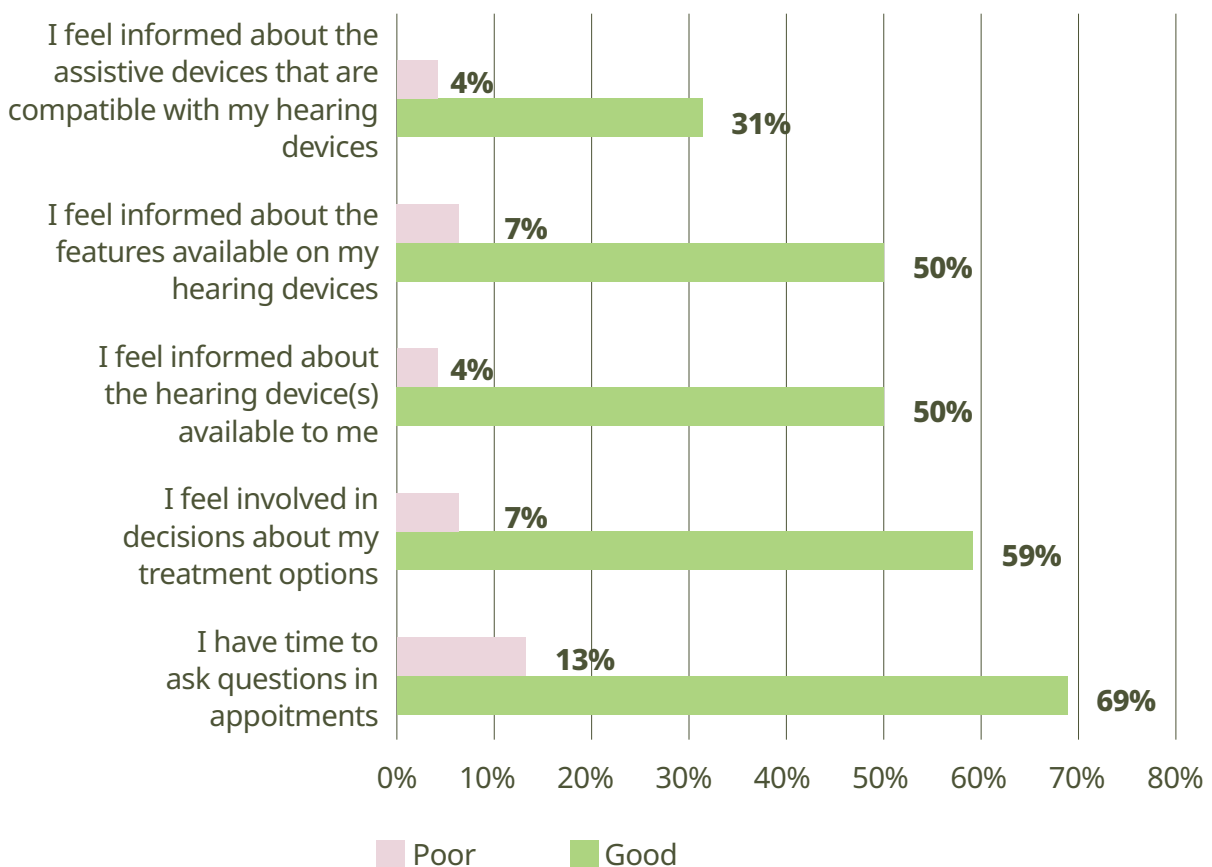
NHS audiology service user

ONGOING SUPPORT

All service users were asked about the ongoing support they receive from audiology. It was found that all users – regardless of whether they used NHS services or private services – feel there is limited ongoing support offered by audiology services.

Poorer ratings of ongoing support (see Figure 2) are related to people feeling less informed about their options and less involved in decisions about their treatment options. Attempts to bridge these information gaps could help to increase patient satisfaction with the ongoing support they receive from audiology services.

FIGURE 2: Percentage of respondents that 'strongly agreed' with each statement by ratings of ongoing support



Only 57% of NHS users rate the ongoing support they receive from audiology as either 'good' or 'very good'. Despite the rating of ongoing support from private audiology services being higher (68%), there is clear room for improvement system wide.

While it was often acknowledged that the NHS is under strain, people are left feeling as though they are not getting the support and information they need.

“Sometimes there is not enough time at the end for me to ask all the questions I might have. I can tell that they have too great of a workload though.”

“Audiologists are just not given enough time to interact fully with me. Everything always feels rushed and I often feel not listened to.”

NHS Audiology Service users

Other areas of frustration include long waiting times when they need an audiology appointment.

“Good audiology services spoilt by long waiting times.”

“Very good when you get to see someone but the wait is several months each time.”

NHS Audiology Service users

People are also disappointed with the limited follow-up from audiology services.

“Unless I try and get an appointment they never get in touch with me.”

NHS Audiology Service user

Some private audiology service users feel the ongoing support is more tailored to their needs, with shorter waiting times and the option of home visits. However, others feel the quality of the service has declined, and that private services are now more focused on selling than on the individual.

“I now feel private service is more focused on trying to ‘sell’ new aids rather than listening to what you believe you need.”

“Over the years I have found that appointments appear to be quicker and less holistic than in the past.”

Private audiology service users

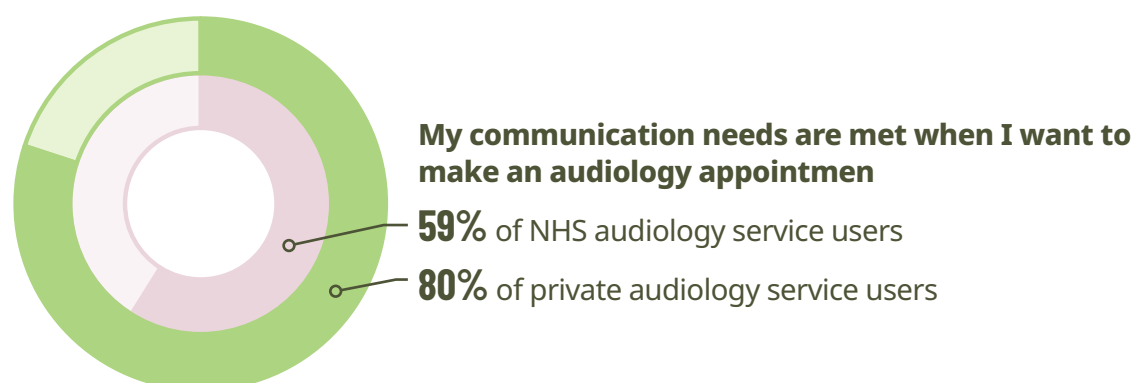
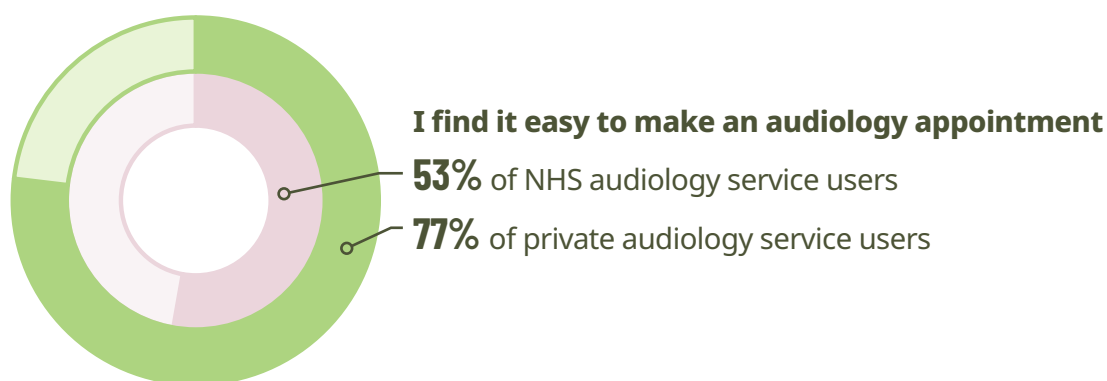
Most people who are deaf, have hearing loss or tinnitus have permanent hearing loss, which needs long-term management. In the UK, more people are living longer, so there is a growing need to better manage long-term conditions and support people to live healthier and more independent lives^{6,7}.

ACCESSIBILITY AND COMMUNICATION

A lack of accessibility when booking and attending appointments is a key barrier, with many suggesting that their communication needs are not being met.

Accessibility when booking appointments

Many adult audiology service users face problems accessing audiology appointments and report not having their communication needs met:



Service users expressed frustration that telephone booking systems do not meet their communication needs and pose a significant barrier to people who are deaf or have hearing loss. For some people, this means they are reliant on other people calling to make appointments for them, creating further barriers to accessing audiology services and impacting on patient empowerment.

“My audiology expects people to phone to get an appointment, this of course is ridiculous for people who cannot use a phone.”

“My NHS Audiology department still call me. I have profound hearing loss and do not take voice calls, which has been stated many times on my notes.”

“Wish there was some way to make an appointment without asking someone else to do it for me.”

NHS Audiology Service users

In contrast, some people have access to alternative booking systems that effectively met their communication needs, demonstrating the varying patient experiences across audiology services.

“I am lucky, my audiology department and audiologist use email very efficiently and quickly and will also use SMS.”

NHS Audiology Service user

Accessibility when attending appointments

A lack of deaf awareness among staff at audiology departments, including reception staff as well as audiologists themselves, is a key source of frustration for service users.

Service users want staff to be trained to have greater deaf awareness and understand how to communicate with a deaf person in order to meet the needs of their patients.

“The reception staff have not been properly trained in how to communicate with hearing impaired people which is not a good start. They just call you and it is easy to miss your name being called.”

“All the staff need training in deaf awareness and how to communicate with a deaf person.”

NHS Audiology Service users

Preferred method of interacting with audiology services

We wanted to know what the current preferred method of interacting with audiology services is for various needs. Most respondents to this survey have long-term experience of audiology services and are an older demographic. In-person at the audiology service is currently the preferred method for:

- **Follow-up after having hearing devices fitted**
- **Sound levels or settings adjusted on hearing device(s)**
- **Getting advice when they had questions about their hearing loss or hearing device**
- **Troubleshooting issues with hearing device(s)**

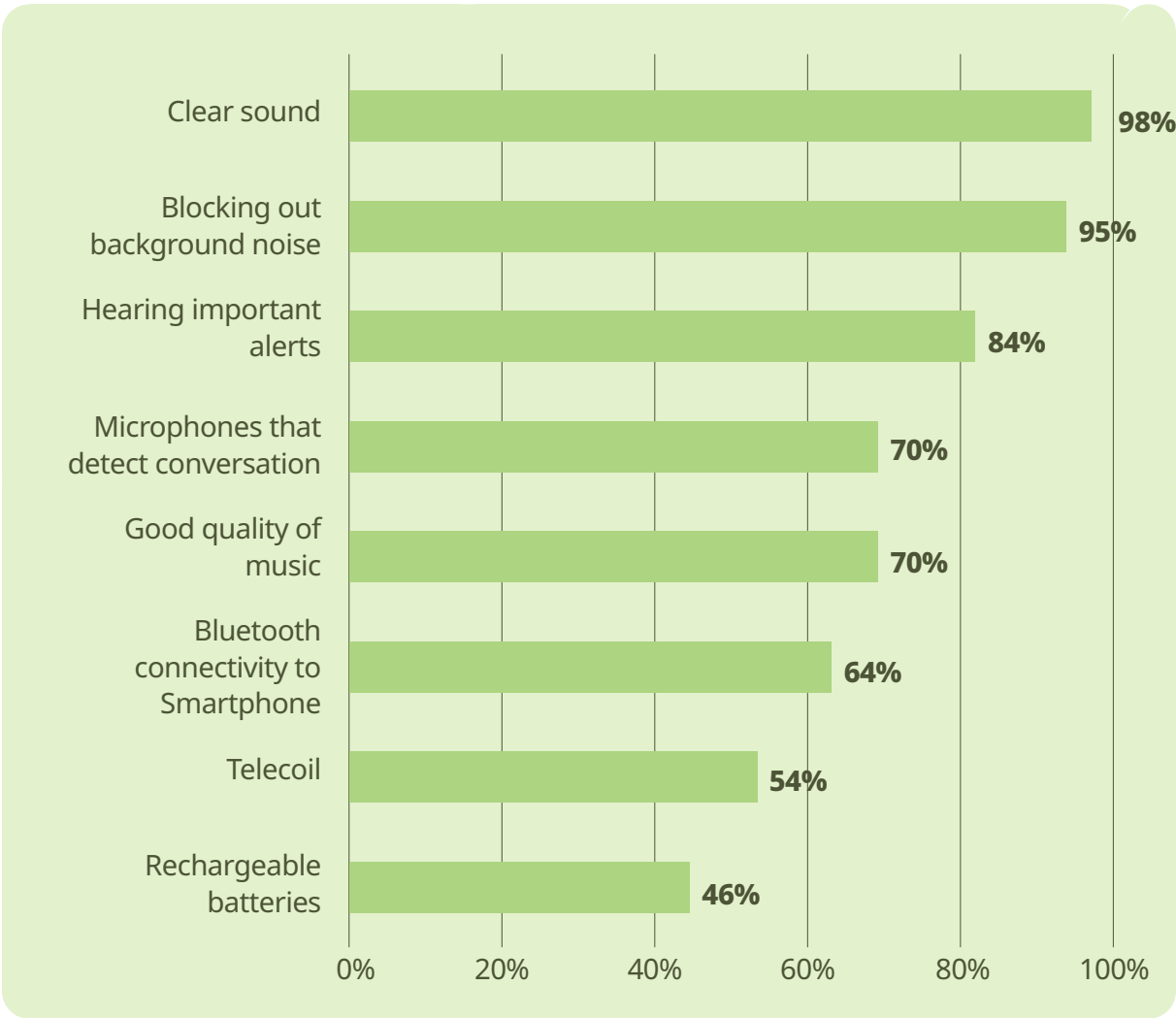
However, despite the preference for in-person support, 34% are interested in having all or most treatment done remotely. There is a currently a preference for in-person support, either at an audiology service or locally at a drop-in clinic, for adjusting hearing devices. However, for some elements of ongoing support, particularly for addressing questions, people have varied preferences, including email and over the phone.



PREFERRED HEARING DEVICE FEATURES

We asked people about the importance of a range of features, even if their current hearing device(s) do not have that specific feature.

Clear sound was rated as the priority feature across all users, the features in order of preference are listed below.



Despite hearing aids being free and available on the NHS, an estimated 5 million people in the UK who could benefit from them do not have them³. For those that use them, there is a strong preference for clear sound, ability to block background noise, and hear important alerts.

IMPROVING THE ADULT HEARING PATHWAY

We asked people what changes could be made to audiology services that would really improve the experience for them. We tested some of our ideas, and 749 people suggested their own ideas for change.

The key themes that emerged include ideas for different service models, improving accessibility and communication, and new technologies that support patient empowerment.

Some of the ideas are already happening in some locations, whereas others are emerging improvements or potentially feasible in the future.

SERVICE MODELS

Remote models

There is very high demand for online support to help with any problems with hearing devices, with 75% of people interested in improvements in this area. There is also demand for remote tuning (48%) and having all or most treatment done remotely (34%). The demand for having all or most treatment done remotely varied by age group, with less demand from older age groups.

People are keen to see improvements that would allow them to adjust the settings of their hearing aids at home through remote adjustments, as well as the ability to experiment with different levels through self-programming.

"Being able to adjust my hearing aid settings at home. Possibly with online or phone support."

NHS Audiology Service user

"As there are now so many possibilities, self-programming using an app for those who feel capable, would be an incredibly useful facility and save time having to keep asking audiology to arrange appointments."

Both NHS and private audiology service user

University Hospitals Plymouth NHS Trust have offered an element of remote care in their adult hearing aid service since 2020. After their hearing aid fitting, people can have fine tuning adjustments made to their hearing aids remotely via an app on their smartphone or tablet. This can be at their request any time via the app, or when the department identify something that can be resolved that way, such as at a telephone follow-up. This saves people a lot of time, effort and money coming to the hospital or clinic to have something done that can be done remotely, and is especially important with a rural population.

Remote care is not compulsory, and people are given the choice of using it, as it's not for everyone, but many people find it helpful. Plymouth also recognises that not everyone has access to this sort of technology, and the department has started working with people in wider digital inclusion services to see how this can be addressed for their patients.

Flexible models

The flexibility of drop-in clinics for minor repairs or adjustments, and battery or tubing changes is suggested as a key improvement.

Those that have experienced them really value drop-in clinics, and are disappointed that many of these have not been reintroduced since COVID.

"Sometimes I know I just need a quick fix but the tendency is to get a full appointment booked in. I'd love to be able to get batteries and tube cleaners from my local pharmacy and then go with more specifics to the audiology team."

NHS Audiology service user



SERVICE ACCESSIBILITY

Accessible communication

Under the Equality Act 2010, and the Disability Discrimination Act 1995 in Northern Ireland, people who are deaf or have hearing loss have the right to equal access to NHS health and social care services. There is also separate guidance and quality standards across the UK, to help services make sure they are [accessible](#).

Despite these regulations and standards, a significant portion of adult audiology service users are not having their communication needs met. People are calling for alternative booking systems and more inclusive spaces whilst waiting or during an appointment.

“Being able to book my appointment online. Trying to phone for an appointment ... the receptionist seems to be oblivious to the fact I have severe hearing loss.”

“Use a board to display appointments or announcements – really think about how your patients will feel on edge having to stay alert listening for their name to be called.”

NHS Audiology Service users

Existing solutions include using a range of contact methods, such as Relay UK and Video Relay, and waiting room facilities, such as visual display systems, flashing or vibrating pagers, and hearing loops.

Local services

Adult service users feel that the availability and accessibility of services could be improved through local delivery, particularly via outreach services in the community or at GP practices.

Local delivery could be particularly useful for repairs, changing tubing, batteries, and ongoing support, which would not only be more convenient for users, but would help to reduce some of the burden on audiology services.

“Community initiatives catering to basic aftercare needs to relieve burden on audiology department.”

NHS Audiology Service user

Different types of local services, such as RNID Near You and community audiology clinics, are already available in some areas. Many of these are delivered by locally established charities.

RNID Near You supports people in their local community with the flexibility of drop-ins for:

- Hearing aid repairs, cleaning, and advice on making the most of hearing aids
- Information on hearing aids, hearing loss, tinnitus, and related issues
- Emotional and practice peer support from people with lived experience

Feedback from hearing aid support users in Northern Ireland found that 84% are using their hearing aids more, and 88% said they are more confident communicating with others. RNID Near You provides support that might otherwise be sought from NHS services. In a survey of over 1,000 users, 87% said they would have contacted their audiology department or GP if this service had not existed in their local area.

Ear wax removal

Many people are frustrated that they cannot access ear wax removal through the NHS. Indeed, 26% of people in our 2022 survey stated they could not afford to pay for private ear wax removal⁵. Beyond the financial burden, significant ear wax build up can leave patients in discomfort, exacerbate tinnitus or create temporary hearing loss, as well as delaying or preventing essential hearing care or diagnosis.

Our recent [ear wax report](#) found that some parts of the NHS in England don't commission the service at all, leaving⁹. 8 million people without access on the NHS if they need it.

People are calling for access to wax removal through the NHS:

"There should be NHS micro suction wax removal readily available as many appointments and delays occur due to having to attend NHS to see if ear wax is a problem and then if it is, having to have micro suction done privately then returning to the NHS afterwards for new ear moulds etc."

"Ear syringing should be more easily available. I have spent a lot privately accessing wax removal, which was vital due to also having hearing loss."

NHS Audiology Service users

TECHNOLOGY AND PATIENT EMPOWERMENT

Adapting the testing environment

There is very high demand for testing hearing devices in a more natural environment than in a soundproof room, with 72% of people interested in this change. People discussed the need for real world testing.

“Facility to check hearing with and without hearing aids in ‘real’ listening situations (what works in a tiny, quiet room does not work in the real world).”

“It would be good to have two appointments a few hours apart when trying out new hearing aids so that I could go outside and walk about away from the soundproof room to try them out and come back for any adjustments straightaway instead of making another appointment.”

NHS Audiology Service users

Better devices

There is also very high demand for a hearing device that automatically tunes itself to your needs, with 86% of people interested in this. Service users want to see access to the latest technology and for a broader range of devices to be made available on the NHS, making full use of the Bluetooth technology that is now available.

“As hearing loss increases, ability to cope with work and life decreases. With everything being remote / contact centre, it’s impossible to function these days without being able to make phone calls, so Bluetooth should be a basic feature on aids provided.”

NHS Audiology Service user

There is also demand for more choice of styles and appearance of hearing devices (49%) and having ear mould impressions saved on file so they can be re-ordered (49%).

Patient empowerment

People want to be more informed about hearing device technology (both through the NHS and privately), helping them to make an informed decision about the best option to meet their needs.

“I was just given my aids and sent on my way and have not really had any assistance or suggestions in the 25 years I have been wearing them.”

NHS Audiology Service user

NHS Tayside Audiology department has recently piloted group hearing aid fittings as a measure to reduce waiting times. Patients see an audiologist for a short initial tuning appointment to ensure the sound is acceptable and hearing aids are comfortable. Immediately after this appointment, they join fellow patients in a small group for a longer session to go through the essentials: how to put their hearing aids in, how to acclimatise to the sound, how to change the batteries and use the controls.

While this has increased the number of patients seen by 25% and significantly reduced waiting times, patients also enjoyed and valued the opportunity to learn about their new hearing aids with peer support, prompting the department to continue testing this model and consider rolling it out across their service.

There is very high demand for more control of hearing device settings (77%), and high demand for more involvement in tuning hearing devices (55%).

"I'd like access to the software so I can make adjustments and experiment with levels. I play guitar and listen to a lot of music and using hearing aids gives a mixed response with little scope for adjustment."

NHS Audiology Service user

"Noise suppression is useful but can end up masking critical safety alarms or approaching traffic for example and needs to be highlighted when patient switches to a suppression mode. As there are now so many possibilities, self-programming using an App for those who feel capable, would be incredibly useful facility and save time having to keep asking audiology to arrange appointments."

Both NHS and private audiology service user

CONCLUSION

Across the UK, millions of people need hearing healthcare but are not accessing it. For those that are accessing support, there continue to be challenges with not having communication needs met, information gaps on available hearing devices and assistive technology, and limited support to adapt to hearing devices.

People are really interested in solutions that incorporate digital products that encourage patient empowerment for managing long-term hearing loss, and ensuring that their basic communication and access needs are met.

In the UK, more people are living longer, so there is a growing need to better manage long-term conditions and support people to live healthier and more independent lives. The solutions people are calling for could both improve their health and save the NHS time and costs in identifying and treating hearing loss.

RNID is calling for:

1. Basic patient communication needs to be met. NHS and private healthcare providers must implement the relevant [accessible information standards](#)

2. Ear wax removal services meet population need. NHS commissioners should follow NICE guidelines to meet their populations' need. For a full set of recommendations, see our latest [ear wax report](#).

3. NHS healthcare providers to test replicating, and scaling existing solutions that address the opportunities for improving the adult hearing pathway. This includes improving service flexibility, the use of existing technology such as Bluetooth, and greater patient empowerment.

4. Greater investment in innovation for audiology. This includes funding to convene service providers and commissioners, technology innovators, patients, and academics; to trial and pilot new initiatives; and evaluate their impacts.



References

¹ Our hearing loss population estimates and hearing loss population projections are calculated using the most robust data available on the prevalence of hearing loss for different age groups (see Davis (1995) and Akeroyd et al. (2020)), combined with the latest available population estimates from the Office for National Statistics.

² Dementia prevention, intervention, and care: 2020 report of the Lancet Commission, The Lancet (2020). DOI: [https://doi.org/10.1016/S0140-6736\(20\)30367-6](https://doi.org/10.1016/S0140-6736(20)30367-6)

³ Gopinath et al (2012) Hearing-impaired adults are at increased risk of experiencing emotional distress and social engagement restrictions five years later. *Age and Ageing* 41(5): 618–623; Pronk et al (2011) Prospective effects of hearing status on loneliness and depression in older persons: identification of subgroups. *International Journal of Audiology*, 50 (12), 887-96; Lin, F. R., & Ferrucci, L. (2012). Hearing loss and falls among older adults in the United States. *Archives of internal medicine*, 172(4), 369–371.

⁴ EuroTrak 2022 UK Survey data and adoption.

⁵ NHS England Diagnostic Waiting Times and Activity Data <https://www.england.nhs.uk/statistics/statistical-work-areas/diagnostics-waiting-times-and-activity/monthly-diagnostics-waiting-times-and-activity/>; Stats Wales, Diagnostic and Therapy Services Data <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Diagnostic-and-Therapy-Services>; Department for Health NI Diagnostic waiting times data <https://www.health-ni.gov.uk/articles/diagnostic-waiting-times>. No data currently available for audiology waiting times in Scotland.

⁶ RNID Access Blocked: The Impact of Cutting NHS Ear Wax Removal Services <https://rnid.org.uk/wp-content/uploads/2022/11/Ear-Wax-Report-FINAL.pdf>

⁷ Chief Medical Officer's Annual Report 2023: health in an ageing society <https://www.gov.uk/government/publications/chief-medical-officers-annual-report-2023-health-in-an-ageing-society> (Accessed December 2023)

⁸ Department of Health & Social Care, Medical Technology Strategy <https://www.gov.uk/government/publications/medical-technology-strategy/medical-technology-strategy> (Accessed January 2024)

⁹ RNID Blocked Ears, Blocked Access https://rnid.org.uk/wp-content/uploads/2024/01/RNID_ear-wax-report_January-2024.pdf

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I:D | Supporting people
who are deaf, have
hearing loss or tinnitus

A registered charity in England and Wales (207720) and Scotland (SC038926).