

Accessibility of Healthcare Services for people with hearing loss in Europe Report

September 2024



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About EFHOH

The European Federation of Hard of Hearing People (EFHOH), established in 1993 and registered in the Netherlands, is a non-profit organization representing hard of hearing and late-deafened individuals across Europe. EFHOH advocates for awareness and practical actions to eliminate barriers to access affordable hearing care and rehabilitation and create an accessible society through public services and assistive technologies. Its main objective is to protect and promote the rights of individuals with hearing loss in Europe, facilitating legislative and social protections through collaboration with members and stakeholders.

Foreword

The World Health Organization Regional for Europe (WHO/Europe) welcomes the publication of the report 'Accessibility of Healthcare Services for people with hearing loss in Europe' by the European Federation of Hard of Hearing People. WHO/Europe is one of WHO's six regional offices around the world. It serves the WHO European Region, which comprises 53 Member States, covering a vast geographical region from the Atlantic to the Pacific oceans.

Funded by the European Union, the document reports on a survey detailing the barriers that persons with hearing conditions face when accessing health services. Communication is at the core of health encounters, and persons with hearing conditions experience diverse communication needs. The report highlights how an enabling environment, awareness of assistive technology, and comprehensive training of the health workforce can reduce the inequities that persons with hearing conditions currently face.

WHO/Europe is providing technical support to Member States towards strong, resilient and equitable health systems. The WHO European Framework for action to achieve the highest attainable standard of health for persons with disabilities 2022–2030 envisages that, by 2030, persons with disabilities and their needs are fully included and considered in all health care planning, delivery and leadership across the Region. The Framework includes targets and specific actions for Member States, WHO / Europe, and national and international stakeholders, as well as a detailed monitoring and evaluation framework, to ensure that the right to health for persons with disabilities, including those with hearing conditions, is fully realized. Furthermore, WHO/Europe is providing technical support towards integrated, people-centred ear and hearing care, as well as helping Member States assess the inclusivity of their health systems using the WHO disability guide for action.

WHO/Europe encourages multi-sectoral collaborations towards equitable access to healthcare services so that everyone, everywhere can exercise their right to health.

Executive Summary

With 59 million people in Europe experiencing hearing loss, many still face significant barriers to accessing healthcare. Hard of hearing individuals have mild to severe hearing loss but often use spoken language to communicate and rely on assistive devices like hearing aids or cochlear implants. The hard of hearing community can also benefit from visual cues, like lipreading and speech-to-text tools, to facilitate communication. Deafened people, conversely, have lost their hearing after having acquired spoken language, and they also face significant communication barriers in non-accessible environments. They may also rely on a combination of spoken language, assistive devices, and visual cues to communicate.

Have lessons been learned? The COVID-19 pandemic exacerbated communication barriers for people with hearing loss, as mask-wearing can obstruct lipreading and dampen sound. Remote consultations often rely on phone communication, complicating understanding and increasing distress during emergencies and health crises. However, the pandemic also drove innovation within the healthcare system, with healthcare providers recognizing the importance of telehealth services and accessible technology. This resulted in greater awareness of accessibility issues, leading some healthcare professionals to offer video consultations with captioning and promote online portals, thus fostering more inclusive practices in healthcare services.

In response, EFHOH conducted a survey from the end of July to the beginning of September 2024, extending to a two-month period, to assess the Accessibility of Healthcare Services for people with hearing loss. This initiative is part of the Citizens, Equality, Rights and Values Programme (CERV), funded by the European Union. The survey was carried out online featuring a combination of 45 multiple-choice, closed and open-ended questions, and collectively reached 92 responses. This approach allowed for the collection of both quantitative and qualitative data, providing a comprehensive view of the experiences, challenges, and barriers faced by individuals with hearing loss. The multiple-choice and close-ended questions offered clear statistical insights, while the open-ended responses enabled participants to elaborate on specific issues. The data presented in this report is based on the responses collected and reflects a wide range of perspectives from hard of hearing individuals across Europe.

Findings show that communication barriers remain a major obstacle to healthcare access for this group. Such obstacles prevent the hard of hearing community from benefiting equally from healthcare services, often resulting in distress and even leading to avoiding seeking care altogether. Respondents underlined several critical areas for improvement, including the need for better communication accommodation, more

awareness of assistive technologies, and proper training for healthcare staff. Despite the existence of assistive technologies, the survey revealed that many healthcare providers are not sufficiently equipped or unaware of how to use them effectively. The survey further revealed that only 13% of respondents had been informed about available communication technology, underscoring a critical gap in accessible healthcare practices. Healthcare facilities rarely offer compatible assistive listening systems for individuals with hearing loss; only 3% of respondents confirmed their availability during visits, while 57% reported that these systems were not provided. Additionally, remote consultations, especially during the COVID-19 pandemic, were not widely accessible to hard of hearing patients, as mask-wearing and reliance on phone communication exacerbated existing issues.

Many respondents stated that healthcare providers lack adequate training to address their needs, resulting in feelings of isolation and inadequacy. The findings revealed that 84% of participants claimed that healthcare staff should improve basic communication skills to meet the needs of people with hearing loss, while 66% highlighted the necessity of understanding assistive technology.

Such results stress the urgent need for systemic changes in healthcare systems to accommodate hard of hearing and deafened individuals more effectively. This survey report serves as a call to action for policymakers, healthcare providers, and institutions to take proactive steps in ensuring equal access to healthcare for people with hearing loss across Europe.

Scope of the Survey

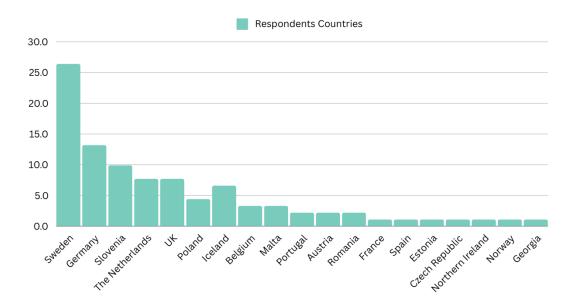
From the end of July to the beginning of September 2024, the European Federation of Hard of Hearing People invited hard of hearing and deafened Europeans to share their views on the accessibility of healthcare services in Europe. The survey is part of the Citizens, Equality, Rights and Values Programme (CERV), funded by the European Union, aiming to assess the accessibility of healthcare services for patients with hearing loss.

Hard of hearing people have the same rights as all European citizens guaranteed by the Pillar of Social Rights on the health and well-being of hard of hearing people. Yet, they often find that services are not accessible to them. The Covid pandemic has especially exposed health services inaccessible to hard of hearing people due to mask-wearing and telephone-only consultations. The purpose of conducting a survey on the accessibility of healthcare services for people with hearing loss was to collect detailed insights into the challenges, inequalities and barriers that hard of hearing and deafened people face daily when accessing such services, based on their experiences. For instance, whether such barriers still exist or just the opposite and whether the accessibility of appointments and availability of communication access have improved.

This initiative underscores the critical importance of understanding and addressing the specific needs of individuals with hearing loss within healthcare systems. By highlighting their experiences, we can work towards creating a more inclusive and accessible environment that ensures equitable access to healthcare services for everyone.

Overview of the Respondents

Overall, the 92 respondents are distributed across various countries, with the largest numbers coming from Sweden, Germany, and Slovenia, followed by the Netherlands, the UK, Poland, Malta and Belgium. The remaining countries, include Portugal, Austria, Romania, France, Spain, Estonia, the Czech Republic, Northern Ireland, Norway, Georgia, and Finland.



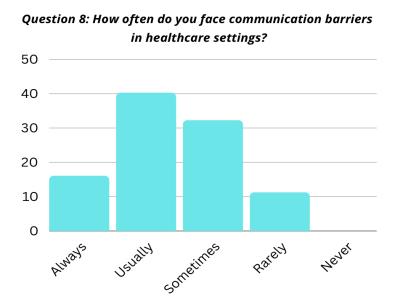
The largest groups were those with severe hearing loss at 42.4% and profound hearing loss at 38%, with only a small portion having mild or moderate levels. Among the respondents, 72% use hearing aids and 32% have cochlear implants. Additionally, 8% do not use any hearing technology. Other responses included various devices such as Roger table microphones, Roger pens and a combination of hearing aids.

Moreover, 41.5% of respondents reported visiting healthcare facilities regularly, while 30.7% indicated occasional visits and 27.4% visited rarely. Primary care and specialty services are the most frequent types of healthcare services, with more than half of respondents. Notably, 8% reported utilizing mental health services.

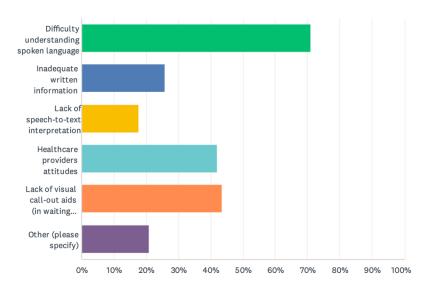
In terms of communication preferences, 87% rely on spoken language, while around 50% also use lipreading and listening. Written notes are another common method, alongside speech-to-text interpreters and apps, sign language, direct microphones connected to cochlear implants, email or e-consult as an initial contact, and texting, highlighting the **diverse communication needs** within the hard of hearing community.

Healthcare Services and Accessibility

Communication barriers in healthcare settings present a significant challenge for many individuals, impacting their ability to access and benefit from healthcare systems equally and effectively. 40% of respondents indicated that they consistently encounter communication barriers, while 16% always face similar challenges. This highlights that most participants regularly struggle with communication difficulties, underscoring the urgent need for enhanced accessibility and communication support for hard of hearing people within healthcare services.



The most prevalent challenge reported with 72% participants is difficulty understanding spoken language. More than 40% also identified the absence of visual call-out aids in waiting rooms as a considerable issue, which hampers their ability to receive timely care. Concerns regarding healthcare providers' attitudes towards individuals with hearing loss were also highlighted by 42% of respondents. Furthermore, inadequate written information presents an additional barrier, together with the lack of speech-to-text interpretation services. Together, these findings emphasize the critical areas where improvements are needed to enhance the accessibility and quality of healthcare for hard of hearing individuals.



Question 9: What challenges do you face when accessing healthcare services?

Other specific issues included:

- Difficulty contacting healthcare professionals or scheduling future appointments due to phone-only communication.
- Discrimination or dismissive behavior by healthcare professionals, including lack of awareness and acceptance of alternative communication methods.
- Challenges caused by plastic screens obscuring mouths, affecting lipreading and dampening the sound .
- A lack of advanced information about healthcare procedures.
- Language barriers enhanced by inaccessible communication.

One respondent from **Sweden** highlighted the challenge of healthcare providers' reliance on phone communication:

"The biggest problem is getting them to accept alternatives to phone calls since the phone is such a default method of communication." (Sweden)

This perspective reflects a broader issue with accessibility, as many participants experience difficulties with traditional communication methods when accessing healthcare services.

The survey underlines a significant gap in communication support, with 65% reporting they did not receive assistance tailored to their needs during healthcare visits. This points to an urgent need for improved communication accommodations in healthcare settings, as numerous individuals are left without the necessary support to engage effectively in their care. For those who did receive support, the quality varied considerably. While around 30% rated the assistance as excellent or good, almost 40%

found it to be fair or poor. This inconsistency suggests that even when support is offered, its effectiveness often relies on the healthcare provider's attitude and commitment to facilitating clear communication.

Overall, more than 30% respondents expressed dissatisfaction with the accessibility of healthcare services for hard of hearing individuals. Several common concerns emerged from their experience, especially phone communication and frustration with having to ensure that a speech-to-text interpreter is booked for their appointments. Others underlined that physical barriers, such as inaccessible visual cues, along with inattentive healthcare staff, who often speak while facing away or refuse to remove masks, further complicate communication.

Furthermore, in the **open-ended question 12 regarding reasons of dissatisfaction with healthcare services**, few respondents shared deeper emotional experiences that underscore the stigma surrounding hard of hearing individuals. One participant from **Sweden** shared their lifelong struggle, stating:

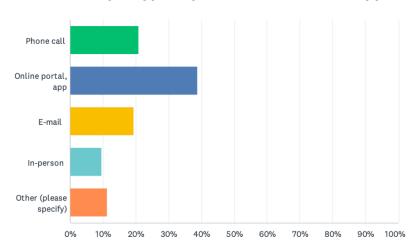
"All my life, since very young, I have had experiences of being treated as an object, a medical patient that needed to be fixed. When I was young, it was very traumatic, and it had a profound effect on my self-view and identity. The pathological treatments over the years made me try to become as hearing as possible; idolizing hearing society and asking for nothing more, to be quiet." (Sweden)

Other respondents reported feeling dehumanized and marginalized, often left to navigate their healthcare experiences without adequate support or understanding. The pressure to conform to hearing norms can create a profound sense of alienation, leading individuals to internalize feelings of inadequacy and silence their identities. These insights not only highlight gaps in accessibility but also raise concerns about the emotional and mental health burden that inadequate healthcare communication can have on hard of hearing people.

The survey reveals that communication barriers severely hinder healthcare access for hard of hearing individuals, with 19% admitting to avoiding seeking healthcare, sometimes due to feelings of embarrassment and frustration. A recurring issue is missing important cues, like their names being called, exposing a lack of accommodation by healthcare providers. Respondents emphasized the necessity of face-to-face interactions to ensure clear communication. The COVID-19 pandemic further exacerbated such communication barriers, as mandatory mask-wearing made it impossible for many to read lips, leading to a reluctance to visit healthcare providers.

Scheduling Appointments

The survey results indicate a strong reliance on digital platforms for scheduling healthcare appointments, with around 40% of the respondents using online portals or apps.



Question 16: How do you typically schedule healthcare appointments?

Nearly 40% of respondents reported having the option to schedule healthcare appointments through online portals and apps. On the positive side, online scheduling can offer a more accessible and efficient alternative, allowing individuals to manage their healthcare with fewer communication barriers than traditional methods like phone calls.

Indeed, nearly half of the participants face challenges when trying to schedule appointments and, when asked to describe such challenges, many expressed frustration with the limitations of phone communication. They stated that background noise and unclear speech make it difficult to hear crucial details like appointment dates and times. The necessity for written confirmation was frequently mentioned, with individuals remarking that mishearing information can lead to missed appointments.

"The anxiety of misremembering or mishearing the dates and hours is always present." (Poland)

"I need to double-check everything." (Iceland)

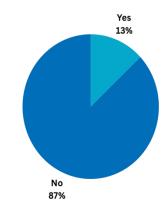
Participants also pointed out that some healthcare providers only offer phone appointments, which can be particularly challenging for those who require face-to-face interactions to communicate effectively. The reluctance of some clinics to adopt modern scheduling methods, such as online portals or email, emerged as a common complaint. These limitations force them to rely on family members or friends for assistance, limiting their right to privacy.

Communication and Assistive Technology

The survey revealed a concerning lack of awareness regarding accessible communication methods in healthcare settings.

Only 13% of respondents reported Question 23: While visiting the health center, are you informed of being informed about available communication methods during their visits, while the great majority were left unaware. This points to a significant gap in healthcare practices, where better communication strategies could improve the experiences of individuals with hearing loss.

accessible communication methods available to you?

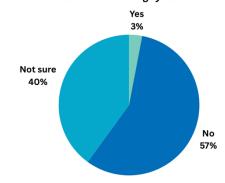


When it comes to informing healthcare providers about hearing loss, most participants confirmed they usually do so. This indicates a generally proactive approach among individuals regarding their hearing status, which can help facilitate better communication with healthcare professionals. However, the use of visual aids or written instructions to help patients understand diagnoses and treatments is still insufficient. 36% of respondents reported only occasionally receiving such support, and almost 40% rarely or never had access to visual aids during their visits.

Regarding assistive technology, over one-third of respondents use personal devices like hearing aids, cochlear implants, or speech-to-text apps during appointments, yet a majority do not. The variety of technologies highlighted, such as the Roger system or live captioning services, underscores the need for healthcare providers to be more adaptable and responsive to the different communication tools patients rely on.

Lastly, the survey results indicate that Question 28: Do healthcare facilities provide compatible healthcare facilities rarely provide compatible assistive listening systems for individuals with hearing loss. Only 3% of respondents confirmed that such systems are available during their visits, while a significant 57% reported that these systems are not provided. Additionally, 40% were unsure, suggesting a lack of awareness or visibility regarding the availability of assistive technology in healthcare settings.

assistive listening systems?



This reflects the importance of recognizing and accommodating individual preferences in healthcare settings to improve accessibility for those with hearing loss.

Emergency Situations and Accessibility

In emergencies, effective communication is critical, but for hard of hearing individuals, this can become a significant obstacle. Conveying and receiving crucial information turns out to be quite challenging. Among the respondents, 60% reported experiencing an emergency, but **only 31% felt they could effectively communicate their needs**. For instance, few reported that the chaotic and noisy nature of emergency settings exacerbates communication barriers with the risk of serious misunderstandings or delayed care.

In addition to environmental challenges, some healthcare staff lacked awareness of the specific needs of hard of hearing patients. Misinterpretations occurred, especially when providers were not fluent in the local language, complicating communication in high-pressure situations. Respondents expressed frustration with healthcare professionals' attitudes, sharing experiences where impatience and rudeness discouraged them from advocating for their needs.

Technology also posed a significant challenge. In some cases, individuals were unable to use phones to communicate in emergencies and understand telephone instructions during an emergency, particularly in loud environments. In other cases, respondents highlighted the absence of assistive devices or the risk of damaging their ones in emergencies.

In critical healthcare moments, the combination of high anxiety, unfamiliar environments, and inadequate communication tools can make it incredibly difficult for hard of hearing individuals to manage their healthcare journey. To improve emergency healthcare services for hard of hearing individuals, respondents highlighted several key areas:

- Use of assistive technology or alternative communication methods: like speech-to-text technologies, apps for emergency contact, visual aids, written instructions.
- **Staff training and awareness**: Regular workshops or training programs on hearing loss, effective communication strategies and understanding of assistive technologies.

"Basic knowledge of dealing with people with hearing loss/deafness is essential. The 'you don't look deaf' reaction and then being handled with skepticism is very tiring." (France)

• Communication preferences:

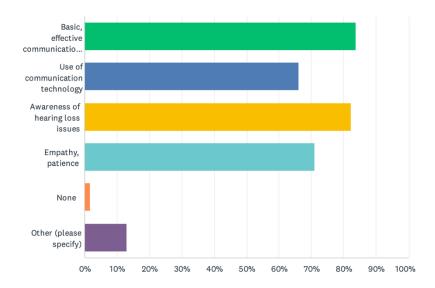
- Flagging hearing loss in medical records to avoid name-call systems and ensure appropriate communication methods.
- Asking patients about their preferred communication method upon intake and integrating their needs for visual, written, or sensory communication into standard practices.
- **Accessible environments:** Providing quiet waiting rooms and soundproof areas to facilitate better communication, alongside clearly marked visual announcements in healthcare facilities.

Healthcare Staff and Training

More than 70% expressed disagreement with the idea that healthcare professionals are sufficiently trained, while only 6% felt the opposite and 21% were neutral.

Participants identified several key areas for improvement, including the development of basic, effective communication skills tailored to individual patient needs, effective use of communication technology, and greater awareness of hearing loss issues. Additionally, there was a notable emphasis on the importance of empathy and patience from healthcare professionals, underscoring a critical aspect of patient care that requires attention.

Question 38: What type of training do you think would benefit healthcare staff to better serve hard of hearing patients?



Specifying alternative responses, several participants suggested specific training approaches, such as collaborating with hard of hearing advocates to share firsthand experiences and perspectives. Additionally, the call for ongoing education is evident, with recommendations for making hearing loss awareness training compulsory for medical staff and providing annual continuing professional development (CPD) certifications. A respondent mentioned, "Often we don't fit into the routines," emphasizing the necessity of adapting communication norms to accommodate patients' needs. Suggestions for practical solutions included training on booking interpreters and captioning services, ensuring adequate time for communication, and providing local resources to assist in these efforts. The findings reveal a pressing need for systemic changes in healthcare training to foster an inclusive environment for hard of hearing individuals.

Feedback and Follow-up Communication

More than 50% of the respondents indicated that they had provided feedback to healthcare facilities regarding accessibility, but only 16% felt that their feedback was acted upon. Some participants expressed a sense of hesitation or frustration, noting that while feedback was provided, it did not always lead to meaningful changes or improvements in the communication and accessibility challenges faced by hard of hearing patients.

For follow-up communication, respondents indicated that they receive information through a variety of channels, including emails (45%), written letters (39%), phone calls (34%) and text messages (32%). Some also mentioned online healthcare portals, inperson consultations, and app-based notifications. However, a notable number of respondents said they do not receive any follow-up communication at all.

In terms of accessibility and clarity, while almost 60% of respondents found the communication consistently accessible and clear, others experienced challenges. 19% reported that communication is often only sometimes accessible or clear, and 12% noted that it rarely meets their needs. This underscores the ongoing difficulties hard of hearing patients face in receiving effective healthcare communication, even with multiple channels available.

Telehealth Services and Accessibility

Most respondents reported using telehealth services infrequently, with more than 70% saying they rarely or never rely on them. E-mail consultations were the most popular format, followed by online chat, video, and phone consultations, but more than half had no experience with telehealth at all.

When asked to describe the communication barriers encountered during telehealth visits, respondents highlighted several recurring challenges. Some mentioned the difficulty of understanding unclear or murky speech, often exacerbated by poor sound quality or noisy backgrounds, and shared their frustration with automated chat services. Phone calls remain a significant barrier with difficulty understanding messages due to the poor quality of the microphone or connection issues. Weak internet signals, blurry or shaky video, and people not facing the camera or covering their mouths during calls further hinder communication. These obstacles underline the need for more inclusive and accessible communication methods to ensure telehealth is a viable option for everyone.

Concluding Remarks

In conclusion, the survey results illuminate critical insights regarding the accessibility of healthcare for hard of hearing individuals, revealing a persistent stigma surrounding hearing loss that significantly impacts patient experiences. Many respondents reported feeling uninformed about the communication methods available to them during healthcare visits, highlighting a systemic gap in training and awareness among healthcare providers. Such lack of understanding contributes to the stigma, making it more challenging for patients to advocate for their needs.

Moreover, while some participants have provided feedback on accessibility issues, a considerable number expressed dissatisfaction with how their concerns were addressed. This points to a disconnect between patient feedback and the responsiveness of healthcare facilities, suggesting that improvements in communication protocols and follow-up actions are necessary. The stigma surrounding hearing loss often leads to assumptions about patients' capabilities, making it difficult

for them to communicate their needs effectively. Many reported experiencing skepticism or dismissal when they mentioned their hearing loss, further exacerbating feelings of isolation and frustration.

The survey also explored the utilization of telehealth services, revealing that many respondents have never engaged with these options. For those who did, barriers such as unclear speech and poor sound quality were common, underscoring the need for telehealth platforms to implement better accessibility features.

Overall, the responses suggest a strong desire for improved training for healthcare staff, focusing on the unique challenges faced by hard of hearing individuals. Many participants emphasized the need for a more inclusive environment that embraces diverse communication methods, such as written communication and the use of assistive technologies. There is a clear call for healthcare systems to become more proactive in recognizing and addressing the needs of hard of hearing patients, ensuring that they receive the equitable care they deserve.

Recommendations

- Implement comprehensive training programs for healthcare staff on effective communication with hard of hearing patients, emphasizing the use of clear speech, empathy, awareness and respect of individual communication preferences.
- Ensure healthcare facilities are equipped with assistive listening devices and that
 patients are informed about their availability. This needs to be combined with
 training for the healthcare professionals on their proper use to enhance patient
 communication.
- Create multiple channels for communicating with healthcare professionals, including online systems, emails and text messaging options, to provide diverse communication needs other than phone calls-only.
- Conduct regular assessments of the accessibility features in healthcare facilities, ensuring they meet the needs of hard of hearing people and are consistently updated.
- Plan healthcare office environments to be more accommodating for hard of hearing people. This includes minimizing background noise in waiting areas,

ensuring proper lighting for lip-reading, and using visual display boards to convey important information via text. For calling out, use display boards or pagers

- Establish protocols that ensure clear and accessible communication for hard of hearing patients during emergencies to ensure that they can respond to emergency instructions.
- Improve the overall accessibility of telehealth services for hard of hearing people, in line with <u>recommendations of WHO</u> standard for accessibility of Telehealth.