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"I always feel like I'm the first deaf person they have ever met" Deaf Awareness, Accessibility and Communication in the NHS: What could we do better?

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Background

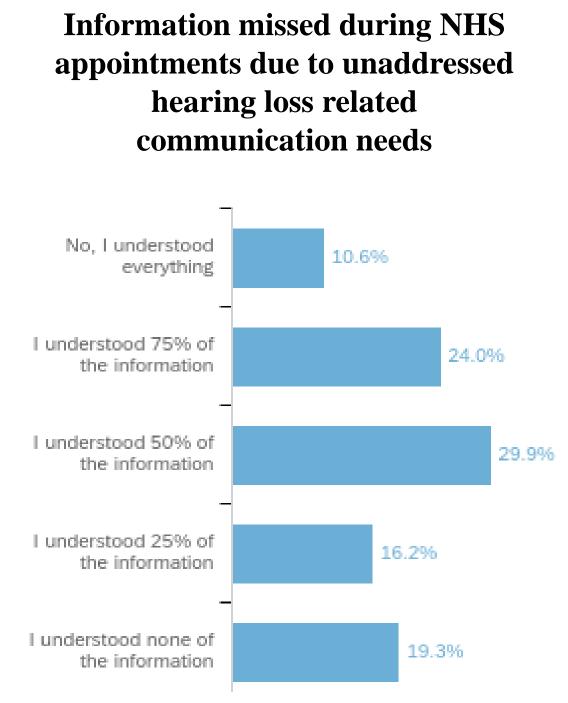
- Few healthcare professionals receive training in Deaf awareness and missed diagnoses and inadequate treatment of deaf and hard-of-hearing patients are estimated to cost the National Health Service £30 million per year.
- Barriers to communication, such as a lack of interpreters, and difficulty accessing health services (for example where telephone-only access is provided) mean that deaf people are less likely to seek healthcare, have poorer access to adequate health information, and consequently experience adverse health outcomes.
- Our working group was created by the British Society of Audiology to understand accessibility, communication and deaf awareness in the NHS. Overall, this group aims to create recommendations and strategies to improve the healthcare experience for deaf people.

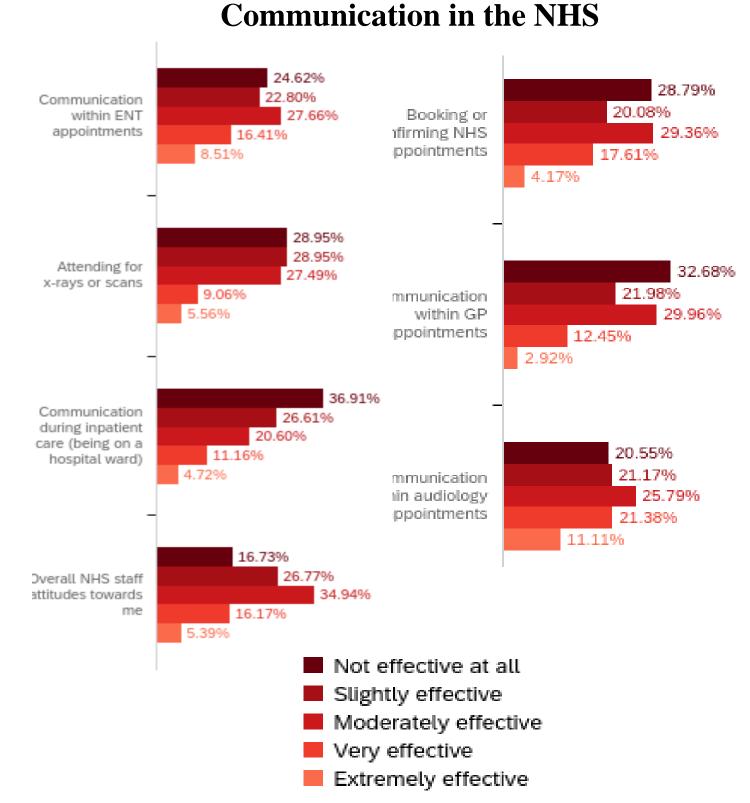
Methods

- A cross sectional survey study focusing on NHS patients' experiences of communication and accessibility in healthcare, using both rating scales and open questions to elicit data on communication barriers faced in NHS settings, and effects on psychological wellbeing.
- BSL videos provided were for survey information/consent and all questions. The survey was created and piloted by researchers and people with hearing loss who have used NHS services.
- The Cambridge University Psychology Research Ethics Committee has provided ethical approval for this study (PRE.2021.076).

Results

In total, there were 549 responses to the survey. Of these, 502 were people with hearing loss who have used NHS services in the last 24 months and 47 respondents were parents/caregivers who have accompanied a person with hearing loss to attend NHS services. 10% of respondents reported that British Sign Language was their preferred language.





Qualitative analysis has identified the following main themes (so far):

- All health professionals need ongoing communication training
 - "getting people to understand that anyone can be deaf..and we are all different and have different needs",
 - "Permanent awareness... have all staff think through what they should do (and what they should definitely not do) if a patient can't hear what they're saying"
- NHS infrastructure is not suitable for deaf people
 - "Very difficult to communicate regarding appointments or making arrangements. Tends to be phone call which means I have to get someone to do this for me or through a text relay system"
- Breakdown of communication across the healthcare pathway impacts patients' emotional wellbeing
 - "It feels like in all settings the system relies on self-advocacy, which can be exhausting"
 - b) "I've hidden away from getting medical help. I've felt mortified and small when I've wasted NHS time due to miscommunication."
 - "I have suffered anxiety and distress and my independence and confidence has been affected"

Conclusion

This study presents the largest cross-sectional dataset of its kind and highlights diverse communication barriers faced by NHS patients with deafness. Understanding service user perspectives can inform the future adaptation and improvement of health services and service delivery. Our working group will use this dataset to create a list of core recommendations for healthcare, to help improve deaf awareness and effective communication across the NHS, including primary care.

References: Jama, Shahidi, Danino, & Murphy. (2020). Assistive communication devices for patients with hearing loss: a cross-sectional survey of availability and staff awareness in outpatient clinics in England. *Disabil Rehabil Assist Technol*, 15(6), 625-628. Action on Hearing Loss. 2015. Hearing matters. https://actiononhearingloss.org.uk/wp-content/uploads/2020/05/Hearing-Matters-Report.pdf. Sign Health. 2014. A report into the health of Deaf people in the UK. https://signhealth.org.uk/wp-content/uploads/2019/12/THE-HEALTH-OF-DEAF-PEOPLE-IN-THE-UK-.pdf. Withers J, Speight C Health care for individuals with hearing loss or vision loss: a minefield of barriers to accessibility. N C Med J2017;78:107-12. doi:10.18043/ncm.78.2.107 pmid:28420772 RNID. 2004. A Simple Cure. A national report into deaf and hard of hearing people's experiences of the National Health Service. http://www.med.qub.ac.uk/DeafAwareHealth/files/asimplecure.pdf Acknowledgements: BP is funded by a Programme Grant for Applied Research (NIHR201608). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.