

Making your research accessible to people living with hearing loss and the Deaf community.



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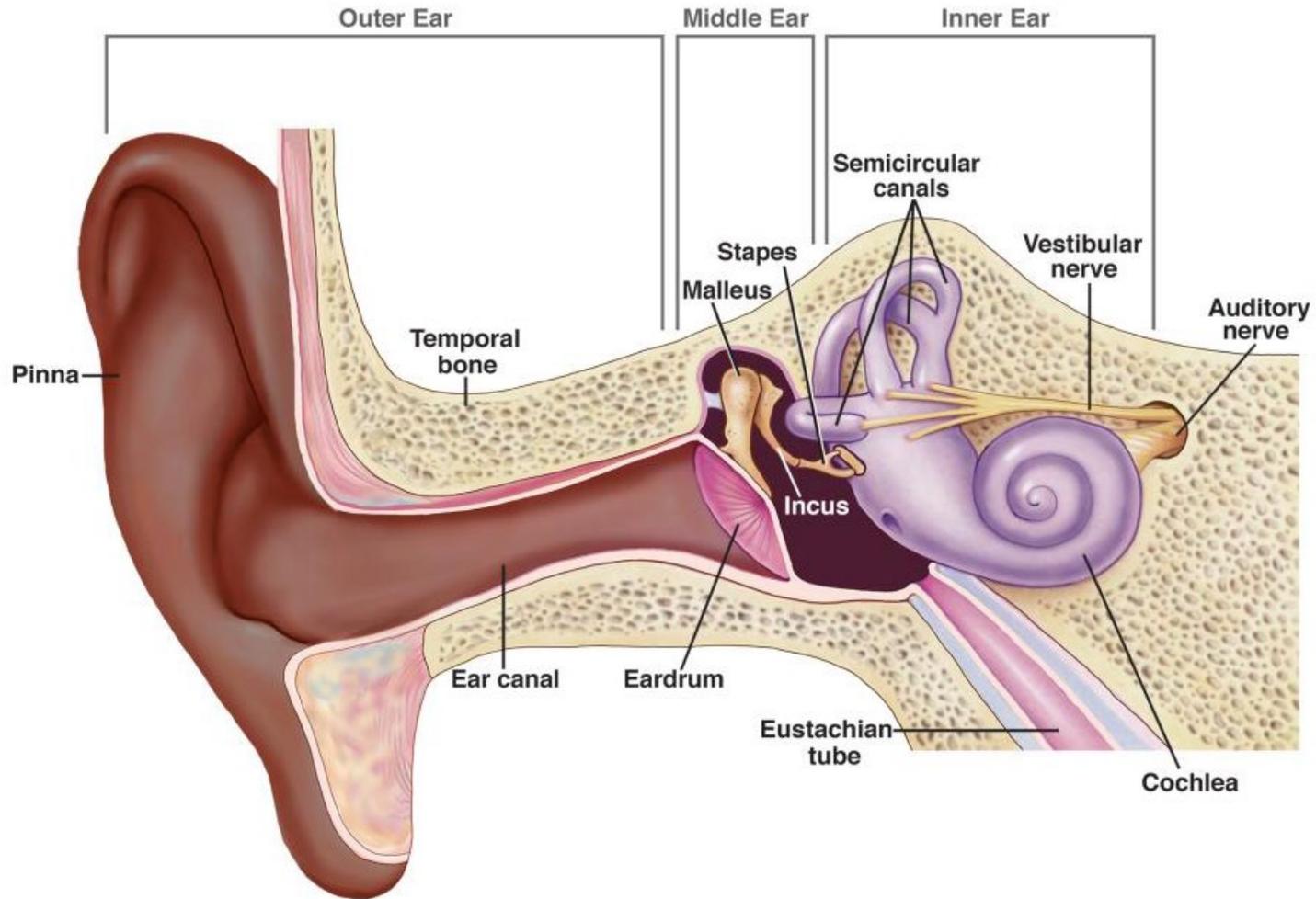
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Importance of Hearing Loss Accessibility

- Very common, affecting 1 in 4 (12.3 million) UK adults.
- Awareness of hearing loss is generally poor.
- People living with hearing loss are recognised as an under-served group in clinical research.
- Poor accessibility impacts participant wellbeing & research quality.
- Making research accessible to this group can also improve accessibility for other groups.

The Ear – Overview of Anatomy



Types of Hearing Loss

Sensorineural hearing loss (SNHL)

- Examples - Age related, noise induced, genetic cause, injury to cochlea or nerve.

Conductive hearing loss

- Examples - Glue ear, perforation, infection or malformation.

Mixed hearing loss

- Combination of SNHL and conductive. Example may be existing SNHL with complication of middle ear infection.

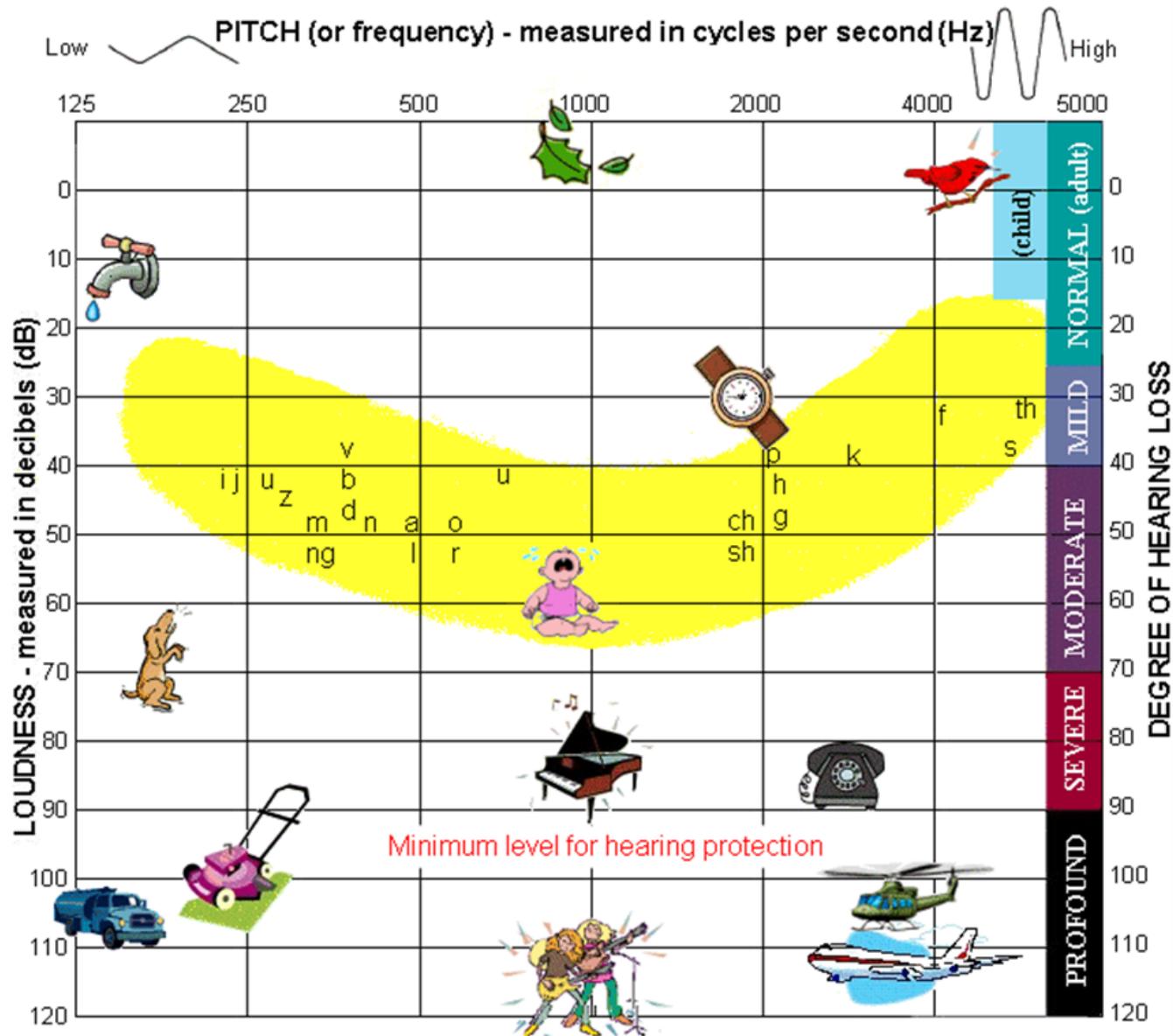
Functional hearing loss

- Reporting of hearing loss with no clinical observed signs under clinical testing.
- Also known as non-organic hearing loss.

Testing for Hearing Loss

- **Pure tone audiometry (PTA)** – Patient responds to a tone at a different frequencies or ‘pitch’, which provides a threshold and overall output of an Audiogram.
- **Tuning fork tests** – used mostly for screening in primary care. Detects conductive or SNHL type or unilateral hearing loss. Does not determine thresholds or levels of hearing (can be normal).
- **Online tests** – RNID and WHO have online Digit-in-Noise tests for self testing. Can be carried out on PCs or Smart phones with own headphones.

Speech Banana & Degrees of Hearing Loss



Management of Hearing Loss

Surgery

- Example: Conductive loss, grommets for glue ear, repair of ear drum.

Hearing Aids

- One side or both (Bilateral).

Cochlear Implants

- Severe to profound loss.
- Involves an implant surgically placed in the cochlea.

Bone Anchored Hearing Aids

- Mostly for conductive loss where surgery or hearing aids are not suitable.

Hearing Therapy

- Hearing tactics
- Speech/lip reading
- Assistive devices
- Access to work

Challenging Situations

- Group conversations / cross-talk.
- Conversations in background noise.
- Conversations on the telephone.
- Poorly lit & reverberant venues.
- Lengthy or demanding conversations.
- Conversations with unfamiliar people.
- Announcements (station, waiting room).

Misconceptions

Hearing aids fix hearing loss.

- Beneficial but do not restore normal hearing. People still have difficulties, especially in early stages & noisy places.

Hearing loss just affects older adults.

- Common in older adults but can affect people of all ages.

Hearing loss is not significant.

- Can have substantial social, psychological, & occupational impacts, especially if untreated.
- Associated with an increased risk of dementia, falls, depression, & loneliness.

The Deaf Community

- Cultural, social and linguistic group with approximately 87,000 members in the UK.
- Mainly use British Sign Language (BSL).
- Have a rich culture and vibrant society, including their own traditions, identity, art, clubs, and networks.
- Tend to view Deafness as a state of being, rather than as a disability, loss, or medical condition.
- Identified by the use of 'Deaf' with an uppercase 'D'.

Hearing Conditions

- **Tinnitus** – Perception of a sound (e.g., ringing, buzzing) when there is no external source for that sound.
- **Hyperacusis** – Everyday sounds are perceived as abnormally loud, painful, uncomfortable, or distressing.

Barriers to Participation

- Researchers/clinicians may lack awareness, training & empathy.
- Previous bad experiences in healthcare or research.
- Hearing loss seen as unimportant, a nuisance, or a joke.
- Potential impact & benefits of research unclear.
- Lack of accommodations, alternatives, & interpreters.
- Poor outreach & lack of opportunities.

What Not to Say

I don't need a microphone. I'll just shout.

Never mind. It wasn't important.

They only hear what they want to hear.

How about we skip the break & try to finish early?

It's just mild. It doesn't bother them.

Making Your Research Accessible

- Improve your **awareness** of hearing loss & Deafness.
- Identify suitable **collaborators** (e.g., experts by experience, hearing research centres, audiologists, charities).
- Obtain the required **resources** (e.g., working loop system, funding for BSL interpreters, phone for texting participants).
- Use suitable and/or multiple **methods** (e.g., focus groups & individual interviews, online & in person).
- Take the lead by informing potential participants that you will make **accommodations** & gather their preferences.

Communication Tactics

- Eliminate or reduce background noise.
- Ensure your face is well lit.
- Face the person & get their attention.
- Speak clearly without shouting.
- Speak at a normal pace.
- Repeat as needed, using different words.
- Non-verbal communication is important.

Research Participation

- Enable participants to bring a relative.
- Provide breaks.
- Shorten/lengthen sessions as needed.
- Provide visual/written information.
- Stick to the agenda content & order.
- Ensure people speak one at a time.
- Provide recaps during group discussions.

Research Participation

- Use concise instructions & questions.
- Spotlight speakers/interpreters (online).
- Show how to use captions (online).
- Speech-to-text apps may help.
- Check you have been understood.
- Ensure emotional support is available.

Venue

- Well lit & quiet.
- Soft furnishings are non-reverberant.
- Separate rooms for break out discussions.
- Separate room for breaks and private conversations.
- Screens with captions at talks/conferences.

Research via Sign Language

- Not a visual/signed version of English.
- Written English is not a substitute.
- Prepare BSL videos for documents.
- Book professional interpreters.
- Speak to & look at the Deaf person.
- Video relay services may help.
- Confirm consent repeatedly during trials.

Key Organisations

- RNID
- Royal Association for Deaf people
- Hearing Link Services
- British Tinnitus Association
- British Deaf Association
- Remark UK
- SignVideo
- SignHealth
- British Society of Audiology

Resources

Simulators:

- University of Southampton: Cochlear implant simulation.
<https://ais.southampton.ac.uk/cochlear-implant/cochlear-implant-sound-like/>
- Starkey: Hearing loss simulation.
<https://www.starkey.com/hearing-loss-simulator>
- Tinnitus UK: Tinnitus simulation.
<https://tinnitus.org.uk/understanding-tinnitus/what-is-tinnitus/>

Resources & Reading

Technology & assistive devices:

- <https://www.connevans.co.uk/>
- <https://rnid.org.uk/information-and-support/technology-and-products/>
- <https://www.bluetooth.com/auracast/assistive-listening/>

Reading:

- Royal College of GPs: Deafness and hearing loss toolkit.
- British Society of Audiology: Guiding Principles of Deaf Awareness in Healthcare Settings (in press).
- David Lodge: 'Deaf Sentence'.

Primary Care Survey

- Share your views on primary care services & research involving adults living with hearing conditions.
- Six vouchers available to be won.



<https://app.onlinesurveys.jisc.ac.uk/s/nottingham/primary-care-survey>



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Thank You

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