

BCIG PPIE

Research findings



What are the most pressing issues for adults waiting for cochlear implants?

- Long waiting lists/assessment processes lead to prolonged anticipation and anxiety as the prospective candidate will be experiencing significantly reduced communication abilities both socially and professionally
- Confusion about the criteria and lack of timely referral from both NHS but especially the private sector who have less incentive or awareness of how and when to make a referral
- Sharing best practice/parity between Centres – funding constraints seem to mean different standards of care and service around the UK
- Getting a better understanding of predicted outcomes and sharing that information with the candidate pre-implant to enable a more informed choice
- Reassurance for the CI candidate about what to expect and consistent contact throughout the assessment process which can be lengthy especially when waiting for surgery
- Availability of bilateral cochlear implants for adults – there is much evidence to support improved outcomes for bi-lateral CI users over unilateral or even bi-modal options and the NICE guidelines are not taking this into consideration.



What are the most pressing issues for adults with cochlear implants?

- Uncertainty over outcomes – rates of progress and the change it can make to their lives which can include disappointment if the outcomes are less than expected
- Anxiety over managing new technology
- Managing background noise and groups
- Long term follow up – the frequency of review appointments at the CI Centre reduces and lead to a sense of being forgotten or can be a barrier to discussing problems as they arise.
- Better access to regular speech therapy
- There is a need for localised support groups for peer support
- It is important for Clinicians to give the CI user full control over the volume and sound adjustment and to listen and act on concerns without patronising – to put the patient at the centre of all care
- Bi-modal fittings should be managed at the Implant Centre – currently compatible hearing aids for certain manufacturers are supplied by local Audiology services leading to frustrations, delays and a very 'one-sided' approach to a person's functional hearing system. We have 2 ears for a reason and need to optimise use of both
- The changing needs of our aging population – management of CI care for isolated adults, those in residential care and hospital. Remote care is not suitable for people who do not have any access to or understanding of technology interfaces or just need assistance with general maintenance
- Music appreciation – over processing sound (AGC) can result in less music enjoyment, pitch perception is an ongoing issue for implant users
- Greater parity of provision to BSL interpretation and accessible information for Deaf CI users across the UK (in house Deaf Advisor being the gold standard) .

" Older children, especially those with progressive hearing losses experience dislocation from what they have previously enjoyed "



Q.3

What are the most pressing issues for children waiting for cochlear implants?

- Barriers to referral and length of assessment – delays reduce communication ability limiting social interaction and inclusion, emotional attachment and family relationships
- Older children, especially those with progressive hearing losses experience dislocation from what they have previously enjoyed –
 - access to education, peer and family relationships, difficulties in participating in hobbies and interests etc. This is very isolating and can have a significant emotional and psychological effect
 - Anxiety about the surgery



Q.4

What are the most pressing issues for children with cochlear implants?

- The change to self identity and self-esteem, especially for older children
- Having to learn to communicate in speech via a new input – anticipation and anxiety and lack of access to regular, accessible and local speech therapy
- Barriers, perceived or otherwise, to achieving life goals – relationships, exams, jobs and training due to deafness/using a cochlear implant
 - Access to Education with appropriate support, specialised teaching and technology to facilitate learning and development
 - Access to free family sign/BSL
 - Social inclusion – promoting awareness and understanding among peers, teachers and the community to overcome social interaction communication barriers

Key issues for...

Adults waiting for a cochlear Implant

- Difficulty getting a referral
- Long waiting lists
- Lengthy assessment process
- Criteria awareness in NHS and private sector
- Predictors of outcomes
- Regular, accessible CI Centre contact
- Bilateral for adults



Children waiting for cochlear implants

- Length of assessment
- Barriers to referral
- Anxiety over surgery



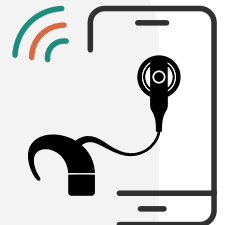
Adults with a cochlear Implant

- Managing expectations
- Managing technology
- Managing background noise
- Long term follow up
- Access to speech therapy
- Access to local peer support groups
- Patient Centred Care
- Compatible Hearing Aids
- Isolated adults
- Music appreciation
- Access to BSL interpreters/Deaf Service Advisors
- Access to a Psychologist/Hearing Therapist



Children with cochlear implants

- Changes to self-identity
- Access to SLT
- Barriers to life chances
- Access to family BSL support
- Social inclusion
- Inclusive access to education and vocational training



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