



Service Quality Committee

IT IS TIME TO TALK ABOUT COCHLEAR IMPLANTS

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INTRODUCTION

Severe and profound (S&P) deafness leads to anxiety, depression and social isolation in some adults (Kim et al., 2017; Carlsson et al., 2015). It detrimentally affects quality of life (Carlsson et al., 2015) and may put adults at risk of Dementia (Lin et al., 2011). Cochlear implants (CIs) are cost-effective interventions that work: they reduce the economic burden of S&P deafness and improve lives (WHO, 2017).

The new NICE guidance '*Cochlear implants for children and adults with S&P deafness*' was published on the 7th March (NICE, 2019). The uptake of CIs by adults is disheartening; 74% of estimated eligible children aged 0–3 years have received CIs, 94% have received a CI by the age of 17, whilst <7% of estimated eligible adults receive one (Raine et al., 2016; Raine, 2013). This is despite evidence showing large, life-changing benefits post-implantation (Ng et al., 2016; Gaylor et al., 2013), the magnitude of which cannot begin to be achieved through the use of hearing aid technology alone (Simpson et al., 2018; Akinseye et al., 2018). Indeed, frequency-lowering technology has been shown to be particularly ineffective at improving high-frequency aided-audibility for individuals who are CI users or CI candidates, resulting in little or no benefit (Hopkins et al., 2014; Hillock-Dunn et al., 2014; Perreau et al., 2013; Park et al., 2012; McDermott & Henshaw, 2010).

An annual report by The Richard Ramsden Centre for Hearing Implants in Manchester, showed average sentence recognition scores in quiet jumped from 10% pre-implantation to 77% post-implantation in their 110 adult patients implanted in 2017-18 (MFT, 2018). Survey responses revealed that 91% of adults felt the implant exceeded their expectations and 100% would recommend a CI to a friend or family member with a similar hearing problem (MFT, 2018).

A study by Ng et al. (2016) found that 86% of implanted adults reported that their CI provided access to communication leading to progression in education and improved career opportunities. Self-reported listening confidence improved at home, at work and socially. Respondents reported less reliance on others and described families becoming 're-connected' (Ng et al., 2016). A recent study by Hughes et al. (2018) found that adult CI users described reduced listening effort and felt more in touch with their own social world; termed 'social connectedness'.

This article will summarise the changes in the NICE CI recommendations for adults and present the evidence behind these changes. Additionally, barriers to CI referral will be discussed along with suggestions for reducing barriers and increasing referrals within a service. Finally practical guidance on assessing and counselling an adult for a CI referral will be offered.

THE NEW NICE GUIDANCE

The final document (NICE, 2019) defines S&P deafness as '*hearing only sounds that are louder than 80 dB HL (pure-tone audiometric threshold equal to or greater than 80 dB HL) at 2 or more frequencies (500 Hz, 1,000 Hz, 2,000 Hz, 3,000 Hz and 4,000 Hz) bilaterally without acoustic hearing aids*' (NICE, 2019, pg5). This is in contrast to the old guidance, which defines S&P deafness as hearing sounds that are louder than 90 dB HL at frequencies of 2 and 4 kHz (NICE, 2009). *Why the change?*

- Low-frequency S&P deafness severely impacts speech understanding (Viney & Moore, 2007). Broadening the frequency range means rising/reverse slope, flat, and downward sloping losses can be considered for implantation.

- The UK currently has amongst the most conservative clinical candidacy criteria for CIs in the developed world. Many countries in Europe have selected thresholds of >70 dB HL as their candidacy criteria (Vickers et al., 2018). The BCIG Candidacy Working Group consensus statements considered the views of 160 CI professionals, CI users and parents of CI users (British Cochlear Implant Group Candidacy Working Group, 2017). When surveyed, 96% of the consensus group agreed that changing the audiometric threshold to 80 dB HL was both appropriate and necessary based on the current clinical evidence. Indeed, 76% of the consensus group agreed that changing the threshold to 70 dB HL was appropriate (although there was uncertainty in the currently available evidence; Vickers et al., 2018). So it appears the new definition of S&P deafness remains conservative compared to our international counterparts.

The new NICE guidelines also re-defines adequate benefit from acoustic hearing aids as ‘*a phoneme score of 50% or greater on the Arthur Boothroyd (AB) word test presented at 70 dBA*’ (NICE, 2019, pg5). This is in contrast to the existing guidance which defines adequate benefit as a score of 50% or greater on Bamford–Kowal–Bench (BKB) sentence testing at a sound intensity of 70 dB SPL (NICE, 2009). *Why the change?*

- The Bamford-Kowal-Bench (BKB) sentence test uses simple language and predictable words e.g. *the clown had a funny face*, therefore cognitive and language ability impacts score. Word tests remove redundancy and provide a more accurate reflection of hearing aid performance (Martin, 1997); additionally phoneme scores can be measured in non-English speaking adults.
- The BCIG Candidacy Working Group consensus concluded that ‘*word-based listening tests are more appropriate than sentence-based listening tests for assessing sufficient benefit from hearing aids in some patients*’ (2017). Doran & Jenkinson (2016) and Vickers et al. (2016) showed that an AB word score of 15% and 18.5% (34.5% phoneme score) respectively on the Arthur Boothroyd word list equates to a score of 50% on the BKB test (when stimuli are presented at the same level). Therefore the new NICE guideline defines ‘adequate benefit’ more generously than ever before i.e. patients can gain considerable benefit from their hearing aids and still be eligible for an implant.

BARRIERS TO CI REFERRAL

Although GPs, other health professionals and sometimes the patient themselves can refer into a CI service, Audiologists are the main gatekeepers to cochlear implants; so why is referral and uptake of CIs so low among adults?

In 2013, Chundu & Buhagiar used a questionnaire to explore UK NHS Audiologists’ understanding of outcomes with CIs, referral guidelines, confidence in making a referral/discussing CIs, and training requirements. Only 48% of Audiologists could confidently interpret the NICE referral guidelines and the same number felt confident discussing CIs with patients and their families. Audiologists felt that more frequent, regular training on referral criteria, benefits, and outcomes was required, preferably at their own local centres but other suggestions included workshops at CI centres, online training and manufacturer training (Chundu & Buhagiar, 2013).

Raine et al. (2016) proposed the following six reasons for low CI uptake in adults:

1. *Acceptance of deterioration of capacity with age.*
2. *Presence of a partner who supports and ameliorates overall effect of such HL.*
3. *Lack of awareness.*
4. *Failure of primary care to propose CI treatment.*
5. *Failure of audiology units to propose CI treatment.*
6. *Poor health and reluctance to undergo surgery. (Raine et al., 2016; page 43)*

Raine and colleagues surveyed awareness of CI candidacy amongst a group of UK Audiologists pre- and post-training. Fifty-three Audiologists took part in surveys and training seminars. Pre-training, across a range of audiograms, 68% of Audiologists were able to correctly identify CI candidacy. Skislope loss caused considerable confusion with just 24% correctly identifying candidacy pre-training, this figure rose to 98% post-training. Correctly understanding how factors such as learning difficulties, BSL use and age affects CI candidacy doubled following training. Interestingly after this study finished the implant centre noted a three-fold increase of adult referrals into their service.

At the BAA conference, Sarah Allen from The Ear Foundation presented the results of a soon-to-be published report titled '*Addressing the low uptake of cochlear implants amongst adults: Audiologists' views of the barriers and facilitators for referral*' (Allen, 2018).

Interviews and survey responses suggested four key themes:

1. *Patient concerns:* these could include surgery, loss of residual hearing, concerns over old age, lack of awareness, uncertainty of benefit from CIs. Patients were also concerned about practicalities such as; travel, time, costs and commitment. Cultural & social reasons also limited uptake.
2. *Local pathway:* Audiologists felt clear simple referral routes were vital with straightforward paperwork e.g. standardised referral templates/reports. Audiologists often felt there wasn't the time or the opportunity during appointments to discuss CI referral.
3. *Relationship with CI centre:* formal and informal contact between referring centres and CI centres was considered important. Audiologists wanted regular training and updates on the referral criteria, assessment pathway and evidence. Audiologists wanted to know the outcome of assessment for patients they had referred.
4. *Professional issues:* Audiologists felt that discussing CI referral required specialist knowledge and counselling skills. They felt these skills were not sufficiently taught at undergraduate level but instead had to be gained in the workplace through training and support.

These findings suggest that awareness of CIs is low amongst UK NHS Audiologists but that confidence discussing implants and referral rates can be improved with the right training and support. The rise of high-street hearing service providers and the advent of Any Qualified Provider (AQP) mean independent sector hearing services are more involved in supporting adults with S&P deafness than ever before. Awareness of CIs amongst independent sector Audiologists and Hearing Aid Dispensers is currently unknown and requires research.

PRACTICAL GUIDANCE ON ASSESSING AND COUNSELLING AN ADULT FOR A CI REFERRAL

How do I assess against the criteria?

The most reliable approach to assess CI candidacy would be to perform a PTA and an aided AB word test. Both assessments are simple and well used in Audiology services, but what if the AB word list is not available? Evaluating benefit from hearing aids can be done through the use of outcome questionnaires and/or individualised goals and listening needs. If carefully verified up-to-date hearing aids are not helping the patient meet realistic goals (e.g. effectively managing a phone conversation), and their PTA falls within NICE guidelines then an implant assessment will be worthwhile.

How do I talk about implants?

Audiologists at the CI centres are best placed to provide patients with all the information they require to make a decision about whether a CI is the right option for them. When discussing a referral try to encourage patients to make an informed decision. Be honest; tell them you are not an expert in this area of Audiology, answer the questions you can and advise them that the implant team will answer the rest.

Encourage patients away from making decisions in haste; 'I am too old' or 'I don't want an operation' are common responses when CIs are first discussed. Explain that a referral is an opportunity to meet the implant team, including surgeons, and to find out more information. Reassure patients that they don't have to decide if they want an implant until they have been through the assessment and they can withdraw from the assessment at any point (and re-join at a later date if they change their mind). Often patients feel by agreeing to a referral they are, in part, consenting to having an implant and this is not the case.

Introducing CIs to your patient can be done in many ways. Here are a few suggestions:

- Start by discussing the perceptual consequence of S&P deafness. This could include an explanation of cochlea damage and dead regions (Moore, 2001). Having a detailed understanding of their own deafness supports self-management and helps patients make, well-informed, logical decisions about their care (BSA, 2016).
- Manage expectations around hearing aid technology. Ensure patients realise that no matter how good the technology, sounds can't be processed properly by the cochlea so the sound they perceive will always be low-quality/distorted/unclear/scrambled. This helps patients and their families understand why hearing aids often can't help.
- Discussing how CIs work using a diagram of the ear can be a useful way for patients to understand how a CI differs to a hearing aid and why benefit with a CI can be far greater compared to a hearing aid.
- Discuss the benefits that can be gained from CIs (based on average outcomes discussed in the literature). Acknowledge that outcomes can vary but are generally positive and can be life-changing. Reassure patients that the implant team will discuss expected benefit and outcomes in detail after the assessment.

Realistically a CI referral discussion may take 15-20 minutes. You may be asked some difficult questions, some of which you won't be able to answer (*'Which ear will be implanted? How much better will the implant be? How much hearing will I lose? Why haven't I been told about implants before?'*). Patients can feel frustrated that hearing aids can't help them and may even feel angry about their deafness. For some patients consideration of a CI referral is a process that takes place over a number of appointments, involving several family members. Of course, many patients will still decline a referral for an assessment but at least they understand exactly what they are declining, having been given all the information required to make a fully informed decision.

Evidence shows that CIs should be an integral part of the management plan for all adults with S&P deafness. Even if a referral does not lead to implantation, ruling out an implant means you can move forward with supporting your patient through the use of hearing aids, assistive listening devices and counselling.

What resources are useful when discussing implants?

- An information leaflet from your local CI centre. If you don't have one, contact your local centre and they can provide you with some. A list of local centres can be found on the BCIG website (<https://www.bcig.org.uk/type/contact-centre/>).
- A diagram of the ear showing outer, middle and inner ear structures.
- A demo implant and speech processor, available on request from manufacturers. Find out which implants your local centre uses.
- The BCIG website holds a great deal of general information on CIs and what to expect following a referral: <https://www.bcig.org.uk>
- The National Cochlear Implant Users Association (NCIUA) provides a wealth of information for potential candidates for implantation and their families, including a useful booklet titled *'Cochlear Implants: The Experiences of Adults. What's it like actually having a cochlear implant?'* which can be ordered in bulk at a reasonable cost. (<https://www.nciua.org.uk/your-implant/user-experiences/>)
- CI centre websites provide a wealth of information on the local process of assessment for an implant. These sites are particularly useful when discussing the operation:
 - <https://www.nuh.nhs.uk/cochlear-implants>.
 - <https://mft.nhs.uk/mri/services/cochlear-implants/>
 - <https://www.southtees.nhs.uk/services/north-east-regional-cochlear-implant-programme-nercip/>
- A honest and informative blog by an Audiologist who recently had an implant: <https://mynewimplant.wixsite.com/rachel/blog>
- A soon to be published 'stair-case model' which describes potential benefit with CIs (dependent on duration deafness) in different listening situations relative to normally-hearing listeners (Ramirez-Inscoe, 2018; Datta, In Press).

What is an appropriate referral?

Appropriate referral	Details
Adults with ski-slope losses where low frequency thresholds < 1.5 kHz are within normal range.	Electro-acoustic stimulation (EAS) can be provided whereby low frequencies receive acoustic stimulation and high frequencies receive electrical stimulation (Mauch & Boyd, 2016).
Adults with pre-lingual deafness <i>or</i> post-lingual deafness	Outcome will vary depending on duration deafness but both groups gain benefit from implantation (Jones et al., 2018).
Adults who present with an air-bone gap can be referred as long as their air conduction thresholds fall within the NICE criteria.	These adults may have a history of conductive problems and middle ear operations. Their bone conduction may be out of range for a bone anchored hearing device or middle ear implant. The appropriate medical/surgical management should have been fully explored first.
Non-English speaking adults	CI team will assess functional deafness and likelihood of benefit.
Adults with a learning disability	CI team will assess functional deafness and likelihood of benefit. If self-consent is not possible a best interest process should be adopted to enable equal access to the same healthcare options as the wider population.
Adults over the age of 75.	Evidence shows outcome with CIs are as good in adults aged 85+ as they are in younger adults (Wong et al., 2015).
Adults who are deaf-blind.	This group are eligible for bilateral implantation (NICE, 2019; NICE, 2009).
Adults who have air conduction thresholds which fall <i>outside</i> of NICE guidelines but have a progressive loss.	Discuss on a case-by-case basis with your local CI centre.
Adults who have air conduction thresholds which fall <i>outside</i> of NICE guidelines but where dead regions are present (or suspected).	Diagnosed DR based on TEN test results (Bird, 2010). Suspected DR based on severely impaired speech recognition relative to PTA (Moore, 2001). Discuss on a case-by-case basis with your local CI centre.
Adults with long-term deafness and no measurable thresholds > 1kHz (i.e. a corner audiogram), communicating through the use of spoken language <i>and</i> sign language.	Outcomes will be more limited but they may still benefit from implantation (as long as they have been consistent users of hearing aids). Discuss on a case-by-case basis with your local CI centre.
Adults who have lost their hearing due to meningitis.	The cochlea may have become ossified but this will be checked during the assessment process using a scan, so it is important to refer even if the meningitis occurred many years ago.

Adults with significant health problems where surgery under general anaesthetic would not be safe can be implanted under local anaesthetic so discuss on a case-by-case basis with your local CI centre.

Adults with single-sided deafness and severe tinnitus can be given an implant to help speech understanding, spatial hearing and reduce tinnitus perception (Távora-Vieira et al., 2015), but this will require funding through private or local pathways as it does not fall under the NICE guidance. This intervention is currently being evaluated in clinical trials in the UK (Kitterick et al., 2014). Discuss on a case-by-case basis with your local CI centre.

Congenitally deaf adults who use BSL and have no spoken language would not be an appropriate referral as they would not benefit from an implant.

RECOMMENDATIONS: HOW TO INCREASE CI REFERRALS IN YOUR SERVICE

1. Increase your awareness of implants:
 - Contact your local implant centre for training and updates.
 - Ensure you and your colleagues feel confident discussing implants. Departmental training could include talks, workshops, shadowing, observation & peer-review. Auditing referrals can help identify gaps in knowledge and training needs amongst staff.
 - Develop close links with implant centres through visits, emails and phone calls.
2. Increase awareness of implants amongst patients:
 - Empower patients to ask about implants e.g. posters in the waiting room which encourage patients to 'ask your Audiologist'.
 - Arrange group sessions in which patients considering referral can meet CI users.
3. Keep the referral pathway simple and clear. Agree a report template with your local CI centre to save admin time (see example in Appendix 1).
4. If possible, schedule 15 minutes of extra time into hearing aid appointments with adults who have S&P deafness so implants can be discussed. Alternatively, consider prioritising a discussion on CIs above other management options e.g. hearing aid fine-tuning (which is unlikely to lead to significant benefit).
5. Add a section in the notes template for S&P patients specifically about CI referral e.g. *'Was a CI referral discussed, Y/N? If yes, what was discussed? If no, why not discussed?'*
6. Consider novel ways to identify referrals: audit and data-mining can be used to screen large numbers of patients to find potential referrals (Joseph et al., 2018; Grisel et al., 2018). Grisel et al. (2018) screened audiograms from a database containing thousands of patients to identify potential referrals. Patients were then sent information through the post and invited to a face-to-face group information session. This approach could be a useful way to identify the patients in your area who are eligible for an implant under the new guidance and provide information to them in a timely manner.

TAKE HOME MESSAGE

In 2016, Action on hearing loss released a 'Cochlear implant policy statement' which made several key recommendations aimed at government, NICE and NHS hearing services (although it could be argued that *all* hearing services should follow the same recommendations). It was recommended that NICE should review their referral guidelines, and that hearing services should:

1. Follow national standards and guidance to **make sure cochlear implantation is offered as an option for *all* those who could benefit.**
2. **Provide *regular* training and guidance for audiologists** on the referral criteria for cochlear implantation. (Action on hearing loss, 2016, page 4).

NICE have followed these recommendations and updated their guidance, now it's our turn.

In 2018, NICE recommended that following audiological assessment, referral for *all* types of implantable devices should be discussed with adults. This article has focussed on CIs but we as Audiologists are the gatekeepers to all types of implants: Bone-Anchored Hearing Devices, Middle-Ear Implants, Brain-Stem Implants and CIs.

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AUTHOR CONTACT DETAILS

I welcome your comments or suggestions on this topic. If you need any help or support with any of the suggestions made in this article please contact me. This article has been shared with BSHAA, BCIG, CI centre co-ordinators and the University of Manchester so it can be disseminated among professionals and students. The content has been converted into a tutorial for Undergraduate students at the University of Manchester and has been presented orally at the National Cochlear Implant Users Association annual conference in June 2019. If you would like an electronic copy of this article to share amongst your colleagues or to use for training/ education purposes please contact me: ann-marie.dickinson@manchester.ac.uk

APPENDIX 1: EXAMPLE OF A REPORT TEMPLATE

Dear CI centre,

Re: patient name, address, DOB, NHS number.

Please would you assess this patient for a Cochlear implant? Please find their details of their hearing loss and hearing aids below.

Hearing loss: Please find a copy of *all* available PTAs enclosed (to show progression of hearing loss/periods of significant deterioration).

Duration deafness:

Aetiology (if known):

Details of ear surgery:

Current hearing aids: Make and model. Date fitted.

Current hearing aid settings: Verification, programmes/volume, features enabled.

Hearing aid use since onset of deafness: How often are hearing aids worn? How long have hearing aids been used? Have optimally fitted hearing aids been trialled for at least 3 months in the last 2 years? If not, why not? (This is a pre-requisite prior to implantation)

Outcome with hearing aids:

Speech test score (optional), outcome questionnaire scores (optional), informal self-report outcome; e.g. Patient cannot perform their job effectively. Patient is unable to communicate with family and friends. Patient feels distressed, isolated and depressed because of their residual disability. Patient does not feel able to look after their own children safely. Patient cannot effectively manage a conversation on the phone.

General health: Are they seeing any specialists for any health problems?

Any other important information: This could include any fears they discussed with you about implants e.g. surgery, loss of residual hearing etc. This could also include a brief summary of the patients motivation for obtaining a CI - what do they hope the implant will improve?

Please let me know the outcome of your assessment.

Best Wishes,

Copy to: GP & Patient

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