

# Newsletter

NATIONAL COCHLEAR IMPLANT USERS ASSOCIATION

No 78 Spring 2024



## RNID Meeting

### CONTENTS

Page 1	RNID
Page 2	PPIE
Page 3	Adult Care
Page 4/5	Telehealth
Page 6	Enjoy Music
Page 7	AI for CIs
Page 8	SOUND Lab
Page 9	CI Registry
Page 10	AB
Page 11	MED- EL
Page 12	Cochlear

The Royal Institution of Great Britain in London was the iconic venue for a meeting held by the Royal National Institute for Deaf People on Tuesday, 5 December 2023.

Attended by an invited audience of members Harriet Oppenheimer, bought together by David Leader of the Gifts in Wills team, the event was attended by an invited audience of Members and donors. Harriet Oppenheimer, CEO, hosted the event and highlighted the importance of the £10.5 M that RNID spent each year in its work to provide funding for research grants and bursaries to help the 12 million people in the UK who have a hearing loss.

Harriet said that the RNID had three primary objectives in addition to its strategic goals of Inclusion, Employment and Health.

- The research programme.
- The free hearing check programme
- The accessibility programme

All this activity is funded by donations and legacies, Harriet said that RNID has three primary, short-term goals that it's currently focusing on: RNID Near You, developing future research leaders, and NHS hearing checks, including RNID's own hearing check, which can be taken online in only a few minutes, is NHS-approved, and has been taken by over 300,000 people.

Each of these goals feeds into one of RNID's four, overarching, strategic programmes:

- Research
- Employment
- Health
- Inclusion

Dr Tracey Pollard (Research Lead) spoke of the extensive financial support that RNID gave to researchers in order to accelerate the development of treatments for hearing loss and tinnitus. This support is conducted through universities and commercial organisations as opposed to RNID itself directly. There are many stages

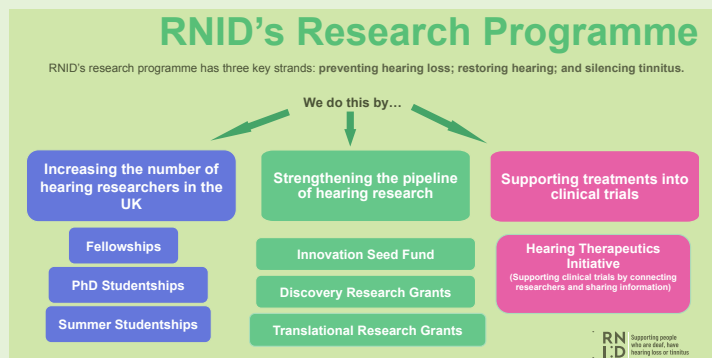


Victoria Boelman, David Leader, Tracey Pollard, Chris Hardy, Harriet Oppenheimer

in the development and approval of funding grants which progressed from the initial proposal through specifications and on to even clinical trials. Currently there are 56 projects in progress. Tracey emphasised that RNID was the only dedicated organisation in the UK for funding of hearing loss research.

Victoria Boelman (Director of Policy and Insight) gave an account on the accessibility program project for On Demand TV subtitles which had begun in 2015. RNID worked closely with RNIB to ensure quotas on subtitling, BSL interpretation and audio description were included in the Media Bill. The Bill was included in the November 2023 King's Speech and is currently making its way through parliament'

Victoria commented on the NHS withdrawal of hearing aids for moderate HL in Staffordshire which was reversed in 2020 after NICE made fresh recommendations on the requirements of such aids in 2019. She added that the RNID was campaigning for free wax removal by the NHS. Dr Chris Hardy gave a talk on hearing loss and dementia.





Anna Tucker

# Involving and Engaging Patients and the Public

The British Cochlear Implant Group (BCIG) last year initiated a Patient and Public Involvement and Engagement (PPIE) group to enhance the quality and impact of their work. PPIE is essentially, in the words of the National Institute of Health Research, about ensuring research and activity “is carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”.

The aim of the BCIG PPIE group is to ensure cochlear implant users and their families/carers inform BCIG projects with lived experience - providing their own unique insight to influence the direction of future projects and be a resource for national researchers and policy makers.

The PPIE Group is made up of cochlear implant users and parents/carers of children with cochlear implants and is co-ordinated by Anna Tucker, herself a bilateral implant user.

The initial brief for the PPIE group suggested by BCIG chair Professor Manohar Bance is to address:

- roadblocks to cochlear implant uptake
- troubleshooting cochlear implant performance
- the usability and design of cochlear implant processors
- screening and testing hearing loss for cochlear implant candidacy
- speech and language development for children and adults using cochlear implants
- the testing of new technologies
- supporting research projects

The group was initially set up on a somewhat ad hoc basis and has recently embarked on a discussion of how best to formalise its objectives and terms of reference, widen its membership and broaden involvement. To this end it is currently, with strong support from Manohar and his colleagues, engaged in mapping the range of existing user and support groups, networks and organizations to try (1) to ensure that their voices (from the National Cochlear Implant Users Association, the Cochlear Implanted Children’s Support Group to smaller local groups) are more effectively heard, and their members informed and involved in activities and research and (2) to broaden BCIG and its members’ pool of experience and knowledge.

The current group has already been involved in such activity as

- commenting on new leaflet publications for users, research proposals and questionnaires

- providing user panel representation at the 2023 BCIG conference
- giving some initial feedback on plans for developing the NHS National Registry of Hearing Implants
- contributing to an audio presentation about cochlear implants for the 2023 British Academy of Audiology annual conference
- producing a briefing for BCIG on the most pressing issues for cochlear implant users
  - see the PPIE section on the BCIG website

BCIG PPIE Group meetings are held online with regular contact between members by email and a WhatsApp group on current projects and discussions.

Group member Steven Kennedy, who had a cochlear implant two years ago at AIS, Southampton says “Had I not had my implant I would now be almost entirely unable to participate in conversations at all. My implant has transformed my life and it is great to be able to give something back by working with a group of like-minded people to try and broaden access and eligibility and improve CI users’ experience and support.’

Tricia Kemp, Group Coordinator of the Cochlear Implanted Children’s Support Group (CICS) and Vice Chair of the NCIUA says ‘Cochlear implants are proven to be safe and effective and are enabling deaf children and adults to have much greater access to the hearing world than ever before. However, we must not be complacent. There is more to be done in raising awareness of cochlear implants and to ensure that deaf people of all ages have equal access to the technology and are well supported throughout their journey. In considering future practices and policies regarding all aspects of cochlear implants it is vital that the voices and views of cochlear implant users of all ages and their families/carers are heard, listened to and acted upon.’

June Statham, a researcher from Wales, says: ‘I was so pleased that I could hear words as soon as my implant was switched on, but I know people’s experiences vary and I would like to support research and development to improve outcomes for CI users’.

If you would like more information about the BCIG PPIE Group, are interested in participating or involving the Group in research, please email Anna Tucker, [annatucker@ci-conversations.co.uk](mailto:annatucker@ci-conversations.co.uk)





Dr Sue Archbold  
Coordinator CIICA

## Improving the standard of care for adults with hearing loss and the role of cochlear implantation



The Task Force have developed Living Guidelines based on an extensive literature review as well as community consultations, engaging with adults with a lived experience of hearing loss, advocacy, and patient groups. This resulted in the development of evidence-based recommendations, spanning hearing loss screening, assessment, referral, specialist evaluation, rehabilitation (initial and lifelong), patient measures and outcomes. The recommendations provide key elements to support practitioners in delivering evidence-based practice. Recommendations are accompanied by good practice statements that provide context to a given recommendation, such as how a recommendation should be implemented in clinical practice, or how it is applied to a specific population or under specific circumstances. Areas such as surgery, intra and post-operative care are well served by existing guidelines. Subsequently the Task Force reviewed and included these guidelines, with appropriate citations and referenced links to original publications.

Supporting evidence collected through the research and community consultations activities is presented for each recommendation, and a Technical Report provides references that informed and supported the guidelines development process. Each recommendation included in this document is preceded by a PROSPERO question.

The Living Guidelines development process has been through a period of public consultation from International Cochlear Implant Day 25th February 2023 until the 31st May 2023. You are still able to provide comments and the Task Force warmly welcomes feedback from all members of the global healthcare community.

You can submit your comments using the feedback tab located under each recommendation in MAGICapp OR by downloading and using the submission template and emailing it to [guidelines@htanalysts.com.au](mailto:guidelines@htanalysts.com.au). All feedback will be considered by the Task Force, to support their evaluation of the recommendations and good practice statements included in the guidelines.

These are the first global guidelines for cochlear implantation in adults supporting the pathway for those adults with severe to profound hearing loss or moderate sloping hearing loss. The recommendations provide a framework through which evidence-based practice can be implemented. Following public consultation, the next step will be for country and regional professional hearing associations and individual practitioners to endorse and implement the guidelines; a process the Task Force and advocacy group Cochlear Implant International Community of Action (CIICA) will support through a range of activities.

Hearing health is a recognised public health priority with prevalence of hearing loss rising worldwide. Currently, there is a lack of awareness and inconsistency in diagnosing and managing hearing loss, especially severe to profound sensorineural hearing loss. Guidelines with clearly defined care pathways for adult cochlear implantation would enable consistent and equitable access to hearing healthcare and treatment.

An international collaboration of hearing experts, known as the CI Task Force, are leading the effort to develop Living Guidelines that will optimise care for hearing impaired adults, improve accessibility, and standardise treatment globally.

### Executive summary

Hearing loss in adults is a common health condition and one of the leading causes of disability worldwide, occurring in 466 million people (6% of the total population). The affects of hearing loss can be wide-ranging, impacting aspects of a person's social and emotional wellbeing, communication, mental health status as well as their working life. Aside from the impact to individuals, hearing loss can place a burden on third parties such as significant others and loved ones. There is also a growing body of evidence suggesting an association between hearing loss in older adults and neurocognitive disorders, such as dementia.

In addition to the impact on the individual and their families, hearing loss imparts a significant economic burden. The World Health Organisation (WHO) estimates that over a trillion US dollars are lost due to hearing loss and measures such as hearing screening are a cost-effective for reducing the burden in adults.

Given the significant impact on society, the WHO made recommendations in their 2021 World Report on Hearing to urge investment in: hearing screening and intervention; disease prevention and management; access to technology and rehabilitation; improved communication; noise reduction and greater community engagement.

In response to this call to action, an independent international Task Force of 52 hearing experts, including those with a lived experience of hearing loss, was formed to address efforts to help reduce the global burden of hearing loss. Three key areas of focus were identified that acknowledge the need to improve access to screening of hearing loss, referral pathways to specialist evaluation and standardising aftercare for cochlear implantation.

# Telehealth

Melanie Ferguson<sup>1</sup>, Cathy Sucher<sup>2, 3, 4</sup>, Emma Laird<sup>5</sup>, David Allen<sup>6, 7</sup>, Isabelle Boisvert<sup>8</sup>,

1. Brain and Hearing, Ear Science Institute Australia, Australia.
2. Curtin Medical School, Curtin University, Australia
3. Medical School, The University of Western Australia, Australia
4. Faculty of Medicine and Health, University of Sydney, Sydney, Australia
5. Incept Labs, Sydney, Australia
6. Department of Linguistics, Macquarie University, Sydney, Australia
7. Melbourne Audiology and Speech Pathology Clinic, University of Melbourne, Australia
8. Vanderbilt University Medical Centre, Vanderbilt University, USA
9. University of Southampton Auditory Implant Service, UK
10. Curtin School of Allied Health, Curtin University, Perth, Australia



Cathy Sucher

Remote telehealth care services have been widely available in many medical fields for years. This is where healthcare services are offered over the phone or online without needing to go and see a healthcare professional in person. This has not been the case for cochlear implant (CI) care. In the past it was difficult to provide remote CI services well, or even at all. Recent improvements in CI technology have changed this. Most CI services can now be accessed online but the use of these technologies remains low. To improve the design and use of remote CI services, we need strong evidence to show that remote CI care is at least as good as face-to-face CI care in clinics. This is important to support industry requests for government, and private health insurance, funding for remote services. But, more importantly, it helps CI users and CI audiologists have confidence in and trust of, remote services. The best way to show if CI care is the same for remote and in-person services is to compare both service options using the same set of outcome measures across many CI users. Outcome measures are tests or questionnaires that assess how well the CI user is getting on with their CI or the CI service. In this way CI users can make informed decisions with CI audiologists about the best way to receive their CI care.

Using the same set of outcomes measures for remote and in-person CI care is also helpful for clinics offering both remote and in-clinic services, which is called hybrid care. Using the same outcome measures also allows audiologists to check the progress of each individual CI user, as well as the progress of all of the CI users cared for by the clinic.

Many CI clinics measure outcomes by how well the CI user can recognise word and sentences. The results of these tests don't always match how the CI user feels they are managing in the real world. Therefore, tests that are more relevant, meaningful, and sensitive to the needs of the CI users are needed. The aim of our study was to bring together a meaningful set of outcome measures that can be used to assess remote CI services.

We identified outcome areas from; 1) studies on the use of remote care for hearing, and 2) workshops with CI professionals and CI users. See tables 1-3 for examples of outcome areas. Adults from Australia, the UK and USA, including 114 CI users and 74 CI audiologists took part in the study. They completed three surveys, over three months, where they rated the 58 outcome areas in order of importance. In the last survey, participants ranked the top 12 outcome areas in order of importance for three main themes; Service, Clinical, and Self-report. The results are shown in Tables 1-3.

For the Service theme, CI users and CI audiologists generally agreed with which outcome areas were most important. The three most important areas to measure for each group were;

1. How reliable the service is,
2. How easy it is to use, and
3. How easy it is to access the service.

In the Clinical theme, there was less agreement between CI users and CI audiologists on the importance of outcome areas. The only outcome area both groups felt was important to measure was the ability to tell the difference between words. CI users also felt it was important to measure how well they could recognise words and sentences. For CI clinicians the most important thing to measure how well the internal implant is working.

For the Self-reported outcome theme, CI users and CI clinicians did not agree at all about which outcome areas were the most important to measure. Many of the areas ranked as most important by CI users, were ranked as far less important by CI clinicians.

The top three most important outcome areas to measure for CI users were;

- 1) *the impact of hearing on everyday life,*
- 2) *hearing-related quality of life*
- 3) *satisfaction with the CI*

CI clinicians' top three most important outcome areas to measure were;

- 1) *expectations of hearing outcomes,*
- 2) *motivation and readiness to do something about hearing difficulties*
- 3) *the acceptability and tolerability of the CI*

In the past, CI clinicians have decided which CI outcomes are the most important to measure. There has been little input from CI users about what outcomes are meaningful to them. Our research has found that what is important for CI users is not necessarily the same as what is important for CI clinicians. As a result of this, it is important that both CI users and CI audiologists understand these differences to make sure that the needs of each group are better understood.

We are now working to select a set of outcome measures for each of the most important outcome areas. Use of the same set of meaningful outcome measures by a large number of CI clinics will help provide the evidence needed to support the use of remote care.

We would like to thank all the CI users and professionals who took part in this study. We look forward letting you know about the next stage of the study in the near future.

**Figure 1 Service Theme**

Top 13 outcome areas for Assessment of the delivery of remote services. Ratings from highest to lowest by CI user rating.  
\*Clinician satisfaction with the service was only asked of the CI professionals, not CI users. Blue arrow indicates level of importance from High to Low. Dashed line indicates agreement within top three outcome areas.

Outcome area	CI user rating of importance	CI audiologist rating of importance
<i>How reliable the remote service technology is</i>	1	3
<i>How easy it is to use the remote service technology</i>	2	1
<i>How easy it is to access the remote service technology</i>	3	2
Additional care required if the remote service can't provide that care	4	10
Satisfaction with the remote service (CI user)	5	6
How acceptable and tolerable is the remote service	6	4
How convenient is the remote service for the CI user	7	7
How efficient is it to use the remote service for the CI user	8	5
How well the clinician accessed the technology needed for remote care	9	8
Unexpected problems related to the remote service	10	12.5
How efficient is it to use the remote service for the CI clinic	11	9
How convenient is the remote service for the CI clinician	12	12.5
Satisfaction with the remote service (CI clinician) *	NA	11

**Figure 2 Clinical Theme**

Top 12 rated areas for measurement of clinical outcomes. Ratings from highest to lowest by CI user rating\*Device integrity and status was only asked of the CI professionals, not CI users. Blue arrow indicates level of importance from High to Low. Dashed line indicates agreement within top three outcome areas.

Outcome area	CI user rating of importance	CI audiologist rating of importance
Recognising words and sentences in noise	1	6.5
Recognising words and sentences in quiet	2	6.5
<i>Identifying the difference between words</i>	3	2
How well the internal implant is working (ECAP, impedances)	4	8
The softest sounds that can be heard	5	9
The CI MAP settings	6	5
The CI reliability	7	10
Problems relating to the CI (internal device)	8	12
How much the CI is used	9	3
Accuracy of the CI measure remotely compared to in clinic	10	11
Unexpected problems occurring when the CI is used	11	4
Device integrity and status *	NA	1

**Figure 3 Self-report Theme**

Top 12 rated areas of self-reported CI user outcomes. Ratings from highest to lowest by CI user rating. Blue arrow indicates level of importance from High to Low. There is no agreement between groups.

Outcome area	CI user rating of importance	CI audiologist rating of importance
Impact of hearing on everyday life	1	10
Quality of life (hearing-related)	2.5	8
CI user satisfaction with CI	2.5	7
Mental health and well-being	4	6
Motivation and Readiness to take action regarding hearing	5	2
Social connections and amount of socialisation with others	6	9
Acceptance of, and adjustment to hearing loss	7.5	4
Acceptance of, and adjustment to CI	7.5	5
Self-belief and confidence to manage hearing health	9	13
Feelings of control & power over own life, determination to change	10	12
Acceptability and tolerability of CI	11	3
Quality of life (general health)	12	14
Expectations of hearing health & hearing devices	13.5	1
Level of hearing difficulty	13.5	11



Cynthia Lam

# Are you a music lover?

We all have our favourite tunes, but have you ever wondered how you actually experience music? While many people say that they couldn't live without music, for people with cochlear implants, their musical journey takes a different path.

At the SOUND Lab, University of Cambridge, we are exploring how we can enhance musical listening experiences for cochlear implant users. In one of our recent studies, we discovered that while people with cochlear implants are listening for changes of a single note in a three-note chord, they were better at doing the task when the middle note was lowered than when the highest note was raised (Figure 1). We also found that older participants with more years of implant experience performed better in the chord discrimination task (Figure 2).

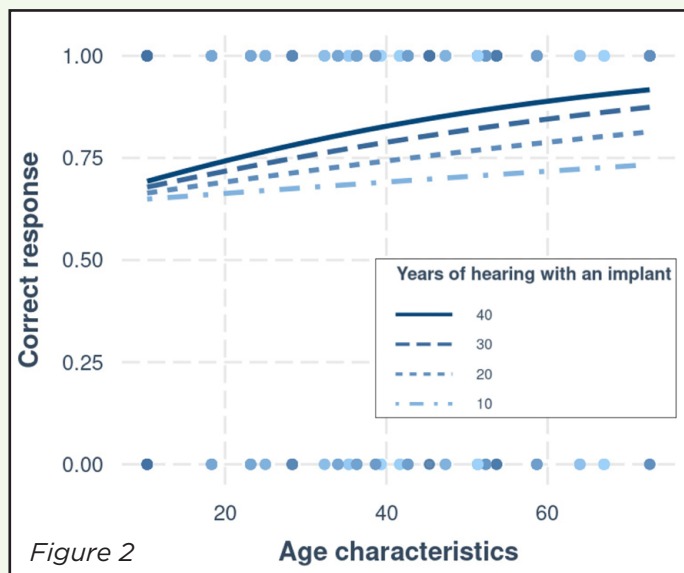


Figure 2. Older participants with longer experience of hearing with an implant showed better performance in chord discrimination

The light blue box indicates lower scores for the highest note raised than for middle note lowered (peach box).

Our ongoing research takes this investigation a step further. We are diving deep into understanding how cochlear implant users can tell different tones apart and if they use special listening approaches to do the task. Tones presented together can create what we call "beats", which are wobbles in the sounds when

they mix together. We want to know if cochlear implant listeners make use of these beats cues to hear differences between tones and if so how it affects music enjoyment and speech perception. Our study looks at when different tones are played in the same implant channel (producing beats) or are spread across multiple channels. This helps us understand the role of beat cues when listening to music or speech. We are hoping to work with 24 cochlear implant users (all implant makes) to run our listening tasks and complete a music listening questionnaire. Our early results show that many cochlear implant listeners can use beats to hear the differences between tones in lower pitches (ranging from frequencies of 262Hz to 392Hz) but not the higher pitches (from 1046Hz to 1568Hz). We are also investigating how these cues help (or don't help) with chord discrimination and speech perception in noisy environments.

By understanding more about the music listening needs and mechanisms behind music perception, we aim to develop training tools and approaches to mapping cochlear implants to enrich hearing experiences for cochlear implant users.

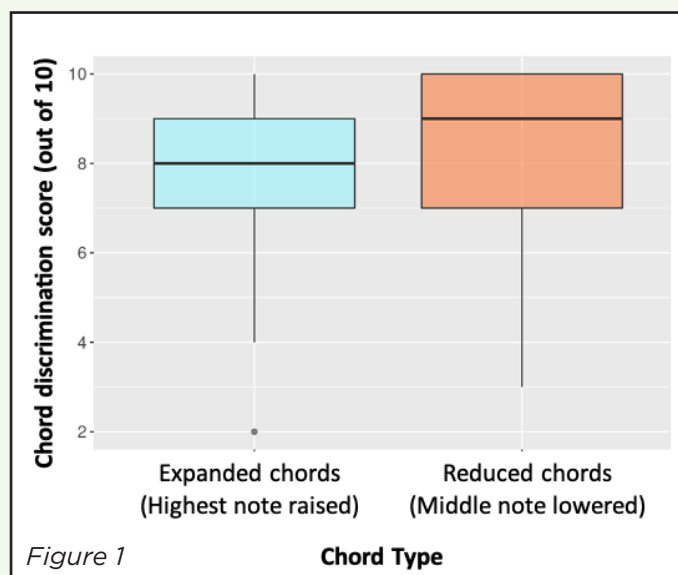


Figure 1. boxplot to show group results on the three-note chord task. The boxes show where most of the data points are. The horizontal line in the box is the median (the middle data point).

QR codes are familiar nowadays and using one's mobile phone, takes one straight to our website - [nciua.org.uk](http://nciua.org.uk)  
Photograph the QR Code above then click the website that appears



Dr Tobias Goehring,  
MRC Cognition and  
Brain Sciences Unit

## AI for CI - what can Artificial Intelligence do for Cochlear Implants?

Cochlear implants (CIs) provide a sense of hearing to more than a million people worldwide. This success story was made possible by a variety of technological and clinical innovations across several research areas and by linking academia and industry. As a result, speech understanding is often good for people that hear with CIs, but there remain limitations in background noise or when listening to music. Complex mixtures of sound are difficult to disentangle for humans and machines alike.

In recent times, there have been remarkable developments in artificial intelligence (AI). While some speak of an “AI revolution” that will reshape every aspect of our life, many consider it a transformational technology similar to the invention of the wheel, electricity or the internet. Some of the most impressive demonstrations of AI’s capabilities include generative language models such as ChatGPT, defeating the human champion of the game Go or solving the folding problem of proteins. All these AI systems have in common that they learn from vast amounts of data, through trials and errors from many millions of examples.

So what about AI for CI? There are many opportunities to improve CI outcomes, from surgical techniques over clinical fitting to daily usage. AI algorithms could potentially help surgeons during CI insertion to maximise hearing function. They could make CI adjustments during clinical appointments more efficient and more effective. And they could be used in daily life to filter out unwanted sounds to make it easier to hear the voice of a speaker of interest in noisy situations.

Communication can be difficult in daily life. There are many situations in which other sounds interfere with the speech sounds that we want to hear, for example at work, school or in social gatherings. In these situations, AI can help enhance speech sounds of interest while attenuating other background sounds. Before AI, this was only possible by using multiple microphones to restrict the input sound to a certain direction, most often from the front. However, this directional sound processing would exclude speech sounds from other directions, for example from besides or behind the listener. With AI, it is now possible to build noise-removal techniques that are much more effective than previously and that work with speech from any direction or just one microphone. The key difference is that AI can better distinguish between sounds of interest and other unwanted sounds, for example people chatting in the background.

AI algorithms learn to remove background noise from speech sounds from millions of examples. Each example is a short recording of a speech sentence mixed with background noise. The AI algorithm first has to identify the speech within that mixture, and its errors are then used to fine-tune and improve the algorithm parameters before the next example is processed. This is called supervised training, whereby the AI algorithm learns from its own mistakes and

gets better over time. The AI algorithm consists of many artificial neurons, inspired by the structure of the human brain. Each artificial neuron has a few parameters that define its function, and these parameters are learned by the AI algorithm during training. Powerful computers and millions of sound recordings are required for training AI, the more the better. Once the performance reaches a threshold of minimal mistakes, the training is stopped, and the AI algorithm can be used to filter out speech from background noise, for example with a CI.

Researchers have shown the potential of AI algorithms to improve speech perception for CI listeners in background noise. Several studies concluded that both the intelligibility and the quality of speech signals were successfully enhanced by the AI algorithms. Before these AI algorithms can be used with CIs, their speech processor needs to be updated with more computing power and stronger batteries. Further work is also required to make robust AI algorithms that perform reliably in acoustic situations that were not part of the training. Researchers and engineers are currently preparing these systems for future CIs.

While humans have two ears to localise sound, AI algorithms can learn to use multiple microphones to localise and disentangle sounds from different directions. They can utilize this directional information to improve the noise-removal performance. They can also extract characteristic voice features to identify a specific speaker. These voice features can be used to inform the AI algorithm to focus on a person of interest, for example a friend or partner, when being in a noisy setting with many people. Such AI algorithms could benefit CI listeners in everyday listening.

In the near future, advances in AI will make it possible to choose which sounds to include or exclude from the acoustic environment, and by how much, into a personal sound mix. Individual users may then incorporate their own requirements and preferences accordingly. The AI algorithms should be trained to keep important alerts and warning sounds, as well as a natural sound quality. There is still some way to go to achieve this, but the prospect is exciting for its potential to improve listening in noisy environments for many people.



Generated by ChatGPT (DALL-E) for the prompt:  
*Make a visualisation for how AI can improve hearing in noisy social gatherings in the future.*



Dr Deborah Vickers Principal Research Fellow



Dr Liam Collins-Jones, Post-Doctoral Research Associate



### Research updates from the SOUND Lab

Here are brief summaries of a selection of research projects in cochlear implants that are underway at the SOUND lab. We have included some paediatric and adult work because we thought both might be of interest.

#### Improving Access to Hearing Healthcare

We know that only a small number of adults who would benefit from a cochlear implant end up getting one. Some research shows as little as 5% of adults in the UK who need a cochlear implant actually get one, and this number is even smaller within our minority communities. To help address this issue, Jane Gallacher, in her PhD studies, is looking at the challenges to accessing implants within South Asian communities and trialling new ways of engaging with this community to improve their hearing healthcare. Jane is also investigating hearing screening for all over 55's to determine if it increases the number of adults who use hearing aids or cochlear implants. The pilot work is additionally backed by the Scottish Government. As part of this work Jane is exploring deaf awareness and accessibility within NHS services, getting researchers, doctors, charities and patients to work together – we will publish the findings in the new year!

#### Improving Sound Quality for Music and Speech

Louis Villejoubert, in his PhD studies is working towards improving sound quality for cochlear implant users. Louis has been looking at how typically hearing listeners hear music using sounds that mimic how cochlear implants users hear. In this work, we've found how different perceptions of sound quality relates to the position of an implant in the cochlea. In the upcoming year, we will test our findings with cochlear implant users to see whether we can improve the sound quality through cochlear implant adjustments.

#### Shining a Light on the Brain

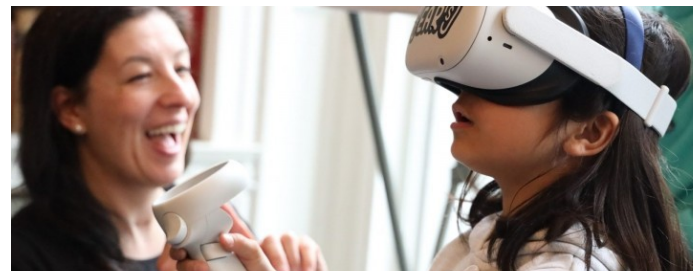
In 2024, we will be starting a project using a new method to look at how the brain responds to sound. This method uses a cap that shines harmless infrared light onto the head to measure activity in the brain, and is called diffuse optical tomography. We'll be using this method in the New Year to see how the infant and adult brains responds to sound. In this project, we aim to find markers of brain activity than can be used to assess how well a cochlear implant is working. We welcome Liam Collins-Jones who has just started at the SOUND Lab in November 2023 and look forward to welcoming Addison Billing later in 2024. This work is funded by the Cambridge Biomedical Research Centre.

#### Language Across the Years

Deborah Vickers, has been working with speech and language therapists, Julie Hare and Tracey Sear at University College London Hospitals to understand how language outcomes in children with cochlear implants have changed for the 20-years to 2019. There are now many more children who reach the age-appropriate level for their language skills. However, about half of children with a cochlear implant still have a language delay after 5-years of listening with their implant. This underlines the importance for researchers and practitioners to work with families to make sure that children are using their implants effectively and are engaged in listening and communication as much as possible.

#### The BEARS project

How do we get both ears to work together? Many people using bilateral cochlear implants or one cochlear implant with a hearing aid have said that they would like to improve their listening to take full advantage of having two implants. In 2023, we launched a UK-wide clinical trial with bilaterally-implanted children aged 8-16 to evaluate the benefits of using the Both Ears virtual reality training suite- BEARS for short. BEARS uses games to train spatial listening (telling where sounds come from) to improve everyday listening, especially in noise. We have recruited over 90 people to take part in this important research and we're excited to get more participants and more results from the BEARS project in 2024! This work is funded by the National Institute of Health and Care Research (NIHR).



#### Contact details for the SOUND Lab

University of Cambridge,  
Department of Clinical Neurosciences,  
Herchel Smith Building, Robinson Way.  
CB2 0SZ. UK.

Deborah Vickers ([dav1000@medschl.cam.ac.uk](mailto:dav1000@medschl.cam.ac.uk))

<https://www-neurosciences.medschl.cam.ac.uk/sound-lab/>



# The National Registry for Hearing Implants - Update

Jenny Townsend Principal Clinical Scientist, Head of North Wales Auditory Implant Service



## Background

It has been a very busy year for the National Registry for Hearing Implants (NRHI) steering group, with significant progress being made towards our goal of a registry capturing important information on all implanted hearing devices. The primary aim of this new registry is to improve safety and outcomes for hearing implant users in the UK.



In the last year the NRHI has been adopted under the NHS England 'Outcomes Registry Programme' (ORP). This new programme aims to capture key data on all types of implanted medical devices in order to improve patient safety. The data collected by the ORP will be on two levels: Firstly a single 'core dataset' for all implantable medical devices, which will cover details of the exact device used (including serial number), patient details and the surgeon, date & place of surgery. Secondly, individual specialties can set up additional 'outcome datasets', including clinical information relevant to the type of device. The ORP have funded development of a national online portal for entering registry data. They will also support ongoing data analysis and reporting.

A number of different outcomes will be included in the registry for cochlear implants - these will include clinical information e.g. on hearing levels, aided thresholds and speech scores before and after implant, information on complications and, in a later version, patient-reported outcomes and experiences, measured using questionnaires. Trusts in England have already been told that they will soon be asked to complete core datasets for all implanted medical devices. This will include cochlear implants, auditory brainstem implants and the various types of bone conduction implants. We expect that centres in Wales, Scotland and Northern Ireland will also be asked by their Departments of Health to contribute to the registry.

## Progress so far

A small team of clinical specialists have been working

closely with NHS England, the ORP, and the registry software provider to provide expert clinical input to the NRHI. We have now completed work on the registry dataset and the data-entry platform, and we are ready to start training the pilot centres. A supporting handbook is being developed to support registry users and online training resources are being designed.

We have also begun work on widening patient engagement into the ongoing registry development, via the new BCIG patient engagement group. Our first focus group activity took place in October focussing on patient views on the options for adult PROMs. A second group will consider paediatric PROMs. If you would like to be involved in either of these groups or other patient engagement activity, please contact BCIG ([info@bcig.org.uk](mailto:info@bcig.org.uk)).

NHSE and the NRHI steering group are currently actively engaging with the Welsh, Scottish and Northern Irish governments to explore cross-border arrangements for the NHRI and the wider outcome registries programme.

## Next Steps

A pilot of the NRHI is planned for Spring 2024. The pilot sites will be Guys & St Thomas', Birmingham and Cambridge (plus North Wales if we can get the governance arrangements agreed in time). Rollout to all CI centres is planned throughout 2024.

Once the first data is being collected, work will begin on analysis and reporting, including establishing a committee for this purpose. CI centres will be able to access their own data, with a series of regular published reports produced for the professional and the public. There will be patient/service user involvement at all stages of this process.

Patient reported outcome and experience measures ('PROM's and 'PREM's) will follow in future versions of the registry; the intention is that the registry system will contact patients automatically by email at defined intervals and ask patients to submit their responses into an online portal. Responding by post will also be an option for those who don't have an email address or don't wish to respond online.

## Future developments

Longer term, the NRHI steering group will change focus towards monitoring the quality of the incoming data and developing new outcome datasets for the remaining hearing implant types e.g. bone conduction implants. We hope to make IT links with our clinical systems so we can pull through some data automatically, reducing the load on clinicians. We are also exploring the possibility of linking the registry to manufacturers, to allow a single point of device registration. All these developments will meet strict data governance and privacy requirements.

## Keep in touch

Please feel free to email the registry team via [info@bcig.org.uk](mailto:info@bcig.org.uk) if you have any registry-related questions or comments!



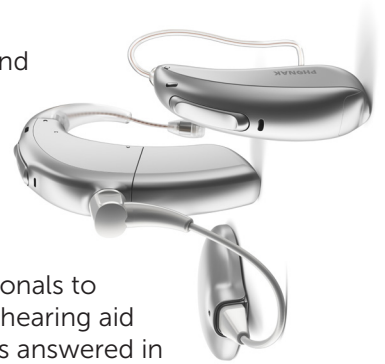
## Marvel CI is now even more powerful with Remote Programming and expanded Linked Two-Ear Solutions

Advanced Bionics is excited to announce CE Mark approval for the latest Marvel CI fitting software and the new AB Remote Support app. Marvel CI now offers even more features to help improve hearing care:

- Remote Programming via a smartphone using the new AB Remote Support app, making hearing care more accessible for cochlear implant wearers.
- Linked two-ear solutions including with a CROS device, allowing more cochlear implant wearers to hear well from both sides.
- Target CI version 1.5, an even more efficient version of our programming software for both cochlear implants and hearing instruments.

### REMOTE PROGRAMMING ALLOWS PROFESSIONALS TO OFFER VIRTUAL CI APPOINTMENTS AND ADJUSTMENTS

Cochlear implant wearers often have to travel long distances to reach clinics for CI appointments. For others, mobility issues or busy schedules make receiving timely and necessary care for their CI and hearing needs challenging. AB's new Remote Support app is not just a remote checking tool, but also allows cochlear implant wearers to have virtual appointments with their hearing care professionals using their smartphone.



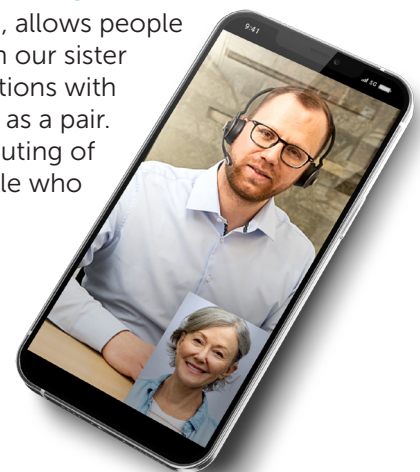
Besides a video chat function that allows CI wearers and professionals to meet over secure connections with end-to-end encryption, it also allows hearing care professionals to remotely and directly adjust the Marvel CI sound processor and compatible Phonak hearing aid or CROS settings. This way, CI wearers can discuss their progress, get their questions answered in real-time, and even receive full CI programming without a visit to the clinic.

To learn more about remote programming visit: <https://www.advancedbionics.com/com/en/home/explore/ab-technologies-innovations/remote-programming>

### EXPANDED LINKED TWO-EAR SOLUTIONS INCLUDING PHONAK CROS DEVICE

Hearing with both ears provides a better sense of where sounds are coming from, allows people to hear better in noisy situations, and makes hearing less tiring.<sup>1,2,3</sup> Together with our sister company Phonak, AB remains the only manufacturer to offer linked two-ear solutions with hearing aids and cochlear implants designed to communicate and work together as a pair. Now AB's Marvel CI will also be the only CI system with a CROS (Contralateral Routing of Signal) device. With the introduction of the Phonak CROS device, AB allows people who hear with cochlear implants more possibilities to hear from all around them.

For people who have severe to profound hearing loss in both ears but hear with only one Marvel CI, having a CROS device on the other ear allows it to pick up sounds from that side and transmit them to the Marvel CI. This way, listeners can have a more complete sense of their surroundings and follow conversations from all directions, especially in noisy situations such as restaurants or in the car. The introduction of CROS makes Marvel the only CI system to offer all hearing options – bilateral, bimodal, or CROS.



To learn more about linked two-ear solutions visit:

<https://www.advancedbionics.com/com/en/home/explore/ab-technologies-innovations/linked-two-ear-hearing-solutions>

# MED-EL

## Blend in or stand out in RONDO 3!



Show off your superpower with MED-EL's cochlear implant audio processor — RONDO 3.

### Wear It Off the Ear

The RONDO 3 audio processor is worn off-the-ear. That means no ear hooks, coils, or cables.

A range of design covers also provides users with the option to either STAND OUT and show it off, or blend in and wear it discreetly, depending on the day. The reusable and fully waterproof WaterWear covers also offer the freedom to hear while enjoying time in the water.

RONDO 3 comes with a range of features to offer easy handling and wireless streaming from smartphones, TVs, tablets, and more:

- Compatibility with all hearing aids
- Wireless charging for simplicity
- All-day battery power
- Superior hearing thanks to dual microphones
- Simple streaming with AudioLink
- Stays in place thanks to S-Vector magnet
- Ready for everyday splashes and rain (IP68 rating\*)

\* Immersion in water (up to a maximum depth of 1 m for 60 minutes).

To find out more about the RONDO 3 audio processor please visit our website or scan the QR code to request a free information pack:



<https://hearlife.medel.com/en-gb/campaigns/rondo3-cochlear-implant-audio-processor#InfoPack>



## REMOTE CARE - THE CARE YOU NEED WHEN AND WHERE YOU NEED IT.

The right hearing care at the right time is important. But getting to the clinic may sometimes be a challenge due to your location, mobility, or work and family responsibilities. Or things may be progressing well, but you'd still like the reassurance of knowing your clinician is monitoring and providing care when it's needed. With Remote Care, you can access care without a visit to the clinic - wherever you are!

### The reassurance of Remote Check

Remote Check is a convenient, at-home testing tool that allows you to complete a series of hearing tests through the Nucleus Smart App, without a trip to the clinic. Your clinician may ask you to complete a Remote Check as a way of monitoring your progress, or instead of a routine appointment. Your clinician decides which Remote Check activities they want you to complete and reviews the results to see if any follow up is needed.

### The convenience of Remote Assist

Remote Assist allows you to have a scheduled video appointment with your clinician through the Nucleus Smart App, so you can access real-time care without a clinic visit. During a Remote Assist session, you can discuss any concerns with your clinician and your sound processor will be connected to the programming software used by your clinician. This means they can make adjustments if needed, and the changes will be automatically saved.

### Are you Remote Care ready?

Your clinician can enrol you in Remote Care if you have a Cochlear™ Nucleus® 8, Cochlear™ Nucleus® 7, or Nucleus® Kanso® 2 Sound Processor. You will also need a compatible smartphone\* and the Nucleus Smart App.

\*For information regarding the sound processors, implants, operating systems and devices that are compatible with Cochlear's Remote Care services, visit [www.cochlear.com/compatibility](http://www.cochlear.com/compatibility).

### Cochlear Family - Feel connected, supported, inspired.

Cochlear Family is part of Cochlear's lifetime commitment. By becoming part of Cochlear Family, you'll be connected to a supportive and inspiring global community of people, just like you. If you are a Cochlear recipient, simply create your free account and you'll have access to a range of educational resources and benefits to help you achieve your hearing potential. Join today at [www.cochlear.com/family](http://www.cochlear.com/family)

### We're on Instagram!

We're excited to announce that we're now on Instagram! We're just getting started but we'd love you to join us there for regular Cochlear news, technology updates and more. We'd love to see how your hearing implants are helping you live your best life - Tag us in your photos and stories! Follow us here [www.instagram.com/cochlear\\_uk\\_ie/](https://www.instagram.com/cochlear_uk_ie/)

### Contact

*Hopefully readers will have enjoyed this edition. What did you think about it?  
What did you like? What didn't you like?*

Please let me have your views so that the Newsletter can be improved.

Please contact me directly at - [editor@nciua.org.uk](mailto:editor@nciua.org.uk)

Thank you - Ed

### National Cochlear Implant Users Association Executive Committee

<b>President</b>	Jackie Ashley
<b>Chairman</b>	Nigel Williams <a href="mailto:chair@nciua.org.uk">chair@nciua.org.uk</a>
<b>Vice Chairman</b>	Tricia Kemp <a href="mailto:vice.chair@nciua.org.uk">vice.chair@nciua.org.uk</a>
<b>Secretary</b>	Dr Ray Glover <a href="mailto:secretary@nciua.org.uk">secretary@nciua.org.uk</a>
<b>Treasurer</b>	Paul Tomlinson <a href="mailto:treasurer@nciua.org.uk">treasurer@nciua.org.uk</a>
<b>Editor</b>	Richard Byrnes <a href="mailto:editor@nciua.org.uk">editor@nciua.org.uk</a>
<b>Webmaster</b>	Richard Byrnes <a href="mailto:webmaster@nciua.org.uk">webmaster@nciua.org.uk</a>
<b>Member</b>	Jenny Burdge

The National Cochlear Implant Users Association (NCIUA) gratefully acknowledges the support and help of the implant manufacturers:

**Advanced Bionics, Cochlear and MEDEL**

**Disclaimer** Whilst the Association uses its best endeavours to provide accurate information on the subject of cochlear implants it does not provide medical advice or make recommendations with regard to any particular implant or equipment and no article in this newsletter should be construed as doing so.

**Registered Address**  
NCIUA, 70 Sycamore Road, Amersham, Buckinghamshire HP6 5DR  
Registered Charity No. 1073222  
Web Site [www.nciua.org.uk](http://www.nciua.org.uk) Email [enquiries@nciua.org.uk](mailto:enquiries@nciua.org.uk)

