

Celebrating global collaboration on INTERNATIONAL COCHLEAR IMPLANT DAY with powerful EURO-CIU manifesto, CI user voices, the launch of the LIVING GUIDELINES initiative and CIICA's 1st birthday!



Global Task Force calls for consistent standard of care guidelines for treating adults with cochlear implants

The formation of a new global **Task Force** was announced today, marking the next step in the creation of '**Living Guidelines**' to set the **standard of care** for adult cochlear implantation. This independent Task Force consists of 50 cochlear implant users and key hearing experts from surgical and audiology backgrounds, representing more than 22 countries.

The Task Force will engage with the **Cochlear Implant International Community of Action (CIICA)**, representing cochlear implant users, other consumer organisations and professional societies to ensure the perspectives of adults with hearing loss are included in the process.

The project goal is to create global living practice guidelines and guidance that can be **adapted** and **adopted** in country, to optimise the standard of care for adults eligible for CI. As 'living' guidelines, they can be updated continuously as new evidence becomes available, as a real-time repository of guidelines under the governance of the Task Force.

AGM and Summer Meeting 2022

This meeting has been arranged for Saturday 11th June 2022. It will be held at the National Council for Voluntary Organisations, Society Building, 8 All Saints Road, London N1 9RL. Further details will be sent to members and will be available on our website: www.nciua.org.uk

6th World Congress of Cochlear Implants in Emerging Nations

This was held in India on 12-14 November 2021. The theme of the meeting was 'Implantable Hearing: Refined and Redefined'. The conference was held virtually with a very user-friendly interface. There were 607 registrations online and most of the three halls, which were dedicated to surgery, audiology and rehabilitation, had an average of 200 attendees on average each day. The next conference will be held in New Delhi in November 2022. Visit www.cigi.in for further updates.

The Case for Change for CI Evidence Briefing 2022

CI International Community of Action, CIICA: a global network, united by a common mission to close the gap in cochlear implant provision and ensure lifelong support for all who could benefit.

CIICA is led by users and family groups, working closely with professional organisations, experts in the field of CI and other stakeholders to increase access to cochlear implantation and lifelong support for those who could benefit from them. <https://ciicanet.org/>

"The cochlear implant is one of the most successful of all neural prostheses developed to date" World Hearing Report, WHO, 2021.

The Growing Global Challenge of Hearing Loss and Deafness

- WHO estimates that 1 in 5 people worldwide live with hearing loss.
- Unaddressed hearing loss and deafness have a huge personal impact: in children they are linked to delayed language and educational attainment, and in adults to social isolation, loss of independence, unemployment, mental health issues, falls, cognitive decline, resulting in the increased use of health and social care service.
- Midlife hearing loss is the biggest risk factor for cognitive decline and dementia (Lamb & Archbold, 2021; Livingstone et al., 2017, Livingstone et al, 2020).
- The Global Burden of Disease Study (GBD) ranks hearing loss as the third most common cause of Years Lived with Disability (YLD) and is the leading cause in the over 70's (The Lancet, 2021).
- WHO (2021) estimates that unaddressed hearing loss costs governments US\$980 billion annually.

Cochlear Implants Change Lives:

Cochlear implants can change this. In adults they have been shown to improve quality of life, reduce depression, improve employability, and improve cognitive functioning. (WHO, World Report on Hearing, 2021)

In children they have been shown to have a positive impact on language development educational outcomes and social and emotional development. (WHO, World Report on Hearing, 2021).

"Children with cochlear implants have greater likelihood of acquiring oral language, integrating into regular schools

and being able to experience sounds along with better speech skills." (WHO, World Report on Hearing, P98, 2021).

"The scope of implantation has been expanded to adults with severe to profound sensorineural hearing loss, who show improved speech perception and health-related quality of life with their use." (WHO, World Report on Hearing, P98, 2021).

The Gap in Provision for CI

In spite of the evidence, globally access to CI is low and provision inadequate.

Globally, only 1 in 20 people who could benefit from an implant receives one.

This gap in provision results in a massive personal and public health issue in dealing with the consequences of unaddressed hearing loss despite the proven benefits of CIs.

Cochlear Implantation – Addressing the Crisis in Hearing Care. The Cost Effectiveness Evidence

- WHO (2021) estimate that for every US\$ invested in ear and hearing care there is a return on investment of US\$16.
- For unilateral cochlear implants, estimations based on actual costs in a high-income setting showed a return of 2.59 International dollars for every 1 dollar invested.
- In one recent study prelingually deaf children with a bilateral CI had a lifetime positive outcome net benefit of €433,000. (Neve et al, 2021)
- Adults and seniors with progressive profound hearing loss and one CI had a total net benefit of €275,000 and €76,000, respectively. (Neve et al, 2021)
- Socio economic costs to Europe of hearing loss exceed 216 billion Euros per year (Shield 2019; www.hear-it.org)

"Early rehabilitation along with use of hearing devices such as cochlear implants are also cost-effective"
Lancet, 2021

Increased provision of Cochlear Implants requires funding and long term sustainable support for users and families. This would be cost effective and save society money while improving lives.

CI International Community of Action, CIICA: a global network, united by a common mission to close the gap in cochlear implant provision and ensure lifelong support for all who could benefit.

CIICA supports users of Cochlear Implants and those campaigning for improved access to this life changing intervention. Our vision is a world where access to CI and lifelong services are available for all who could benefit. To achieve this our goals are:

- To develop a global community of CI advocacy groups, with opportunities to share activities and resources and collaborate to strengthen the user and family voice.
- To provide CI advocates with the tools for change they need to increase access to CI services and improve support after implantation and ensure lifelong care.
- To increase access to the provision of CI and lifelong services globally

NOTES

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WHO World Hearing Report 2021. <https://www.who.int/publications/i/item/world-report-on-hearing>

Do you want to know more? To see the range of global action taking place, share resources and inspiration visit www.ciicanet.org.

HIGHWAY CODE 2022

The new revised Highway Code has just been published. In response to the campaign to encourage more walking and cycling there have been many changes to the code to give the more vulnerable users – walkers and cyclists – more protection. Cyclists, in particular, have been given more protection from cars and motorised traffic. However, as far as pedestrians are concerned, in particular, deaf and hard of hearing people cyclists can be quite a menace.

I am an CI user and have an Advanced Bionics implant and their Chorus processor which I like very much even though it is bulky. I find it a great improvement on my old behind the ear processor. I hear cars coming quite easily, except when it is windy, so I don't have to keep looking behind me, but cyclists are different – I cannot hear them unless they call out and by the time I hear the 'whurr' of the cycle wheels they are almost upon me and it is too late to move out of their way.

I live in a rural area and the one-track road outside my house, on which I exercise my dogs everyday, is a great favourite with cyclists. While car drivers will slow down or even stop, as they are required to do when they meet walkers, dogs and horse riders all over the road it is not the same with cyclists.

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I live in a rural area and the one-track road outside my house, on which I exercise my dogs everyday, is a great favourite with cyclists. While car drivers will slow down or even stop, as they are required to do when they meet walkers, dogs and horse riders all over the road it is not the same with cyclists. While most are very considerate there are some who think they own the road and resent having to slow down. I have nearly been knocked down a couple of times by cyclists who think they can pass walkers closely at speed. Many people do not hear them coming especially those with hearing impairments and, if the walker changes direction ever so slightly, they can be knocked down. Cyclists are supposed to have bells but, unfortunately, the code does not require this as a matter of course and there is no mention of warning walkers and horse riders of their approach by calling out. Even my horse, who has very keen hearing, has been badly startled by cyclists coming up behind at speed and not making us aware of their presence.

The code does provide for fines of £1,000 for dangerous or careless cycling but how do you catch them when cyclists have no registration number!

On cycle tracks where pedestrians and cyclists are not segregated cyclists are required 'to take care when passing pedestrians, especially children, older or disabled people, and allow them plenty of room.' This is very important as more and more cycle tracks are being built and most are not only for cyclists, but also for walkers and sometimes horse riders; in short they are multi user tracks. It's a shame the rule doesn't apply to rural roads as well!

Having had my particular grumble I must admit that the new code does include, I believe for the first time, mention of hearing impaired people. Rule 207 covers 'Particularly

vulnerable pedestrians' and included are 'people with hearing impairments who may not be aware of your vehicle approaching.' Also 'Deafblind people who may be carrying a white cane with a red band or using a dog with a red and white harness. They may not see or hear instructions or signals.' Unfortunately, this all applies to vehicle drivers but not cyclists who are also a danger as, unless they call out or ring their bells, ride up behind people silently. I suppose we are going to have similar problems with electric vehicles which could be even more dangerous than cyclists as they are also silent.

Alison Heath

Manufacturer's News

From Advanced Bionics

Communicate with Success Events

At Advanced Bionics we are committed to supporting anyone considering cochlear implants and our AB cochlear implant wearers and their families. We offer regular virtual events to help support your hearing and cochlear implant journey. Topics range from technology updates to accessing support. See below, for what you can expect from the next series of events:

6th April 2022 - Marvel One Year On

What we have learnt about Marvel CI one year on

22nd June 2022 - Music and Cochlear Implants

Find out how our brains process music, including a guide on useful resources

24th August 2022 - Teens and Cochlear Implants

Resources and advice: from school classrooms to new adventures

5th October 2022 - Who is Roger?

Learn about Roger technology and how it can help in more challenging listening environments

7th December 2022 - Supporting Deafblindness

Learn about how Deafblind UK helps people with hearing and vision loss

15th February 2023 - Understanding Your Programming Appointment

Everything you need to know about your cochlear implant programming appointment

To register for an event visit www.advancedbionics.com/uk-events. Registration links will become available closer to the events.

As well as these group virtual events, we also offer one-to-one meetings. These can be either virtual or in-person at a time and place to suit you. To register for a one-to-one meeting, please use this link:

www.advancedbionics.com/CWS121

For more information email:
hear-uk@advancedbionics.com

We are here to support you!

From Cochlear

Discover the benefits of bimodal hearing

Ears work as a team, and the brain needs both ears to effectively process sound.¹ From crossing the street with confidence to having conversations in noisy places, there are significant advantages to hearing well with both ears.¹

For many people, using a cochlear implant on one ear and

a hearing aid on the other is the combination that provides them with their best hearing.²⁻⁸ This is called **bimodal hearing**.

By optimising the hearing in both ears, bimodal hearing solutions are designed to improve overall sound quality and enhance your hearing in many situations

Direct smartphone streaming

Together, Cochlear and Danalogic offer a bimodal hearing solution with direct smartphone streaming. This means you can stream calls, music and entertainment from a compatible Apple or Android™ device directly to your compatible sound processor and hearing aid*.

Direct streaming is designed to complement your lifestyle, so with just your smartphone you can easily connect with loved ones and the world around you.

- Designed for an accessory-free, richer hearing experience.^{5,10}
- Direct bimodal streaming can improve speech perception in quiet compared with a hearing aid or cochlear implant alone.¹¹
- Apple and Android Low Energy.



“Bimodal [hearing] gives me access to a range of sound which wasn’t available to me before. Direct streaming has opened up a whole world in stereo.” Charlotte, UK

Remote Care

When choosing a bimodal hearing solution from Cochlear and Danalogic, you’re choosing two pioneers in the delivery of Remote Care solutions.

It’s never been easier or more convenient for your clinician to check your hearing health and ensure that you continue to hear your best. All from the comfort of your own home.

Cochlear™ Remote Check offers the option of a convenient, at-home hearing assessment that you can

Cochlear™ Travel Programme

2022 hopefully sees the return of the summer holiday. So, whether you are having a long weekend city break or travelling abroad for some much-needed relaxation by the beach, you want complete peace of mind that you can still have a great time should anything happen to your sound processor.

Hear, there and everywhere

It would be stressful to be without your sound processor at any time, but much more so if you are away from home. The Cochlear Travel Programme means you can enjoy your holiday worry-free, and you can continue to hear all the sounds that are important to you.

complete using your sound processor and compatible smartphone - without having to travel to the clinic.

GN Assist and GN Assist Live allow you the option of either a live consultation via video call, where all changes can be made, or you can request downloadable fine tunings via the BeMore app.

Could bimodal hearing be right for you?

The best way to determine if bimodal hearing could benefit you is to speak to your hearing healthcare professional. Alternatively, you can find more information at cochlear.com

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Full Backup Plan - designed to ensure you won’t miss a moment of your trip.

For full peace of mind, you will take a backup sound processor with you on your trip. With the Full Backup Plan, we send a backup sound processor directly to you before you leave home. You can then enjoy your trip, knowing that you have a replacement sound processor immediately available if you need it.

How the service works

Simply download and complete the Cochlear Travel Programme application form from our website bit.ly/CUKtravel. We require your request a minimum of two weeks before you travel so we can obtain an electronic

copy of your MAP from your clinic. A mapped sound processor will be couriered to your address ahead of your trip, then it's down to you to go and have a wonderful time away not having to worry!

For more information, please contact the Cochlear Travel Programme team on +44 1932 263 640 or e-mail uktravel@cochlear.com.

Discounts available for Cochlear Family members!

Get a lifetime of support with the Cochlear Family

We understand you want to know as much as possible about your device and how to live your life with a hearing implant. We created the Cochlear Family to help educate and inform you so that you can feel empowered to understand and look after your equipment so you can always hear your best.

The Cochlear Family programme recognises your situation and gives you information relevant to where you are in your hearing journey. For example, if you have just got your implant, we know you need information about how to use and maintain your device(s), how to troubleshoot the basics, plus tips for dealing with your day-to-day routine.

Connect and share with others at events and learn from the world's largest hearing implant community¹

There are many other membership benefits included, such as free shipping on purchases from our online store, a 25% discount off the holiday loaner scheme and priority notification about new services and technology and discount offers from Cochlear.

Sign up for free today and start benefitting immediately www.cochlear.com/family

¹ Reference: With more than 440,000 registered Cochlear Nucleus implants worldwide, Cochlear leads the way as the most chosen provider of implantable hearing solutions. D1805413. Cochlear Nucleus Reliability Report, Volume 19 December 2020. 2020, March.

From MED-EL

MED-EL CONNECT WITH YOU

New 1:1 Virtual Appointment System

We wanted to share with you the news of our new appointment system which is available for anyone who has a hearing loss who may be a candidate for a hearing implant, as well as current MED-EL users.

MED-EL Connect with You is a 1:1 appointment booking system which provides candidates and MED-EL users with the opportunity to make a 30-minute virtual appointment with one of our Senior Clinical Specialists.

The service can be used to raise any questions or to gather more information on the topics below:

Implant Choice Information

- Are you considering a hearing implant?
- Unsure which implant is suitable for you?
- Do you need help with considering the options available?



Implant Safety Question

- Do you already have a hearing implant and are due to have a medical procedure and need more information?

Product Information

- New to MED-EL and want to know more about our products, including connectivity tips and tools?

Rehabilitation Information

• Here at MED-EL we have a comprehensive range of rehabilitation tools and resources

Need an appointment?

Visit our website below, select a date and time, add your contact details, then click 'book'. You will receive an

email acknowledging your booking, including a link to join your virtual appointment, it's so simple!

<http://www.tinyurl.com/Medel-Events>



The Relationship between Hearing Experiences, Music-listening Behaviours, Chord-Discrimination and Music Enjoyment for Cochlear Implant Users

Cynthia Lam, Sound Laboratory, Department of Neurosciences, University of Cambridge

Cynthia recently joined the SOUND lab under the supervision of Dr. Deborah Vickers. She completed her BSc in Biochemistry in 2019 from the Chinese University of Hong Kong, and MSc in Translational Neuroscience in 2020 from Imperial College London, UK. Her research interests include music, pitch perception, auditory memory and memory. In her free time, she enjoys filming and editing videos, dancing, swimming and playing the piano.

Background

There are research studies exploring how pre-implant hearing experiences affect speech perception with a cochlear implant (CI). However, there is not much research on if or how pre-implant hearing or music experiences affect music perception or music enjoyment after implantation.

Objectives

The main objective of the study was to explore how pre-implant hearing and music experiences are related to music perception and music enjoyment after implantation. We focused on age characteristics, duration of hearing difficulty and years of implant listening as variables related to hearing experiences. We focused on perceived music quality with the implant, music background and music listening habits as music experiences. We then looked at how these variables were related to chord discrimination and music enjoyment scores.

Chord-discrimination task

The CI users participated in a chord-discrimination task, where they were presented with three chords: two were the same C major chord, one chord was different. They had to identify the chord that sounded different from the other two. There were six chords that sounded different: three were "expanded" chords (where the top notes increased by one, two or three semitones) or "reduced" chords (where the middle note decreased by one, two or three semitones).

Munich Music Questionnaire

The CI users also filled in an adapted version of the Munich Music Questionnaire (MUMU), which was used



to measure the role of music in their lives. Questions were related to everyday music listening habits, music quality ratings, enjoyment of different types of music and different genres of music, sound quality when listening to music, experience with playing music and singing, and music education. They also answered some questions about themselves, which were used in our analyses to understand the influence of hearing and music experiences on music enjoyment and chord discrimination.

Understanding how hearing and music experiences are related to music perception and enjoyment and how they might offer ways of improving the effectiveness of CIs for

music listening and supporting rehabilitation approaches.

Main Findings

Relationship of pre-implant hearing and music experiences to chord discrimination

People using loudspeakers and headphones to listen had higher chord-discrimination scores than for those using Bluetooth streaming. This may reflect “drop-out” effects when using Bluetooth streaming.

We observed that older participants with more experience with the implant scored better in the chord-discrimination task than younger participants with less implant experience.

Among the 6 chords in the chord-discrimination task, participants scored better with minor chords with larger semitone differences. We think this might be because CI users can benefit from using additional cues generated when two notes are close to each other.

Relationship of pre-implant hearing and music experiences, to music enjoyment

Music enjoyment was measured in the questionnaire

Music enjoyment was related to the duration of hearing difficulty and music quality of the CI, where longer duration of hearing difficulty resulted in higher music enjoyment scores when the music quality of the CI was better.

Musical background and music listening habits were

not shown to be related to chord discrimination or music enjoyment.

Some of the hearing and music experiences that have been reported to be related to speech understanding were also shown to be related to chord-discrimination and music enjoyment, but not necessarily following the same pattern as when associated with speech (sometimes longer duration of deafness leads to poorer speech outcomes.)

With these findings, we were able to see that some pre-implant hearing and music experiences have effects on how CI users perceive and enjoy music after implantation, and that the pattern of these effects may be different to what is observed for speech perception. Therefore, in the future, the cues that CI users use to discriminate chords, and how these cues relate to other aspects of music perception and enjoyment, will be explored. Identifying these cues and understanding hearing and music experiences that improve music enjoyment will hopefully contribute to further advances in rehabilitation, fitting, CI processing strategies or hardware that could enhance music perception and enjoyment for CI users. Knowledge of these pre-implant hearing experiences and music experiences can also be incorporated into clinical approaches to improve music engagement for CI users.

If anyone is interested in hearing more about the in-person music and sound-listening tasks that I am setting up in Cambridge, please let me know and I will send further information. We may also have future online experiments. My email address is: cccl4@cam.ac.uk

Implant allows 103-year-old to hear again

by Daniel O'Mahony

From the Telegraph, 14th April 2022

A 103-year-old man from Cumbria is thought to be the oldest person in the world to regain their hearing after being fitted for a cochlear implant. Leslie Hodgson walked in to the James Cook University Hospital in Middlesbrough on his 103rd birthday and asked medics to carry out the procedure. The retired architect who is also registered blind, has been “trapped in a cocoon of silence” since his hearing deteriorated ten years ago, consultant Noweed Ahmed said.

Mr Hodgson also became the oldest person in the world to receive a subtotal petrossectomy – a procedure to clear out the lining of his mastoid, a part of the skull located just behind the ear. That was to resolve issues caused by an earlier ear operation – carried out with a hammer and chisel in 1925.

Mr Hodgson, who is from Penrith, was awake for both operations, which were carried out under local anaesthetic.

National Cochlear Implant Users Association

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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.

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