Newsletter NCIU

NATIONAL COCHLEAR IMPLANT USERS ASSOCIATION NEWSLETTER



Using vibration on the wrists to enhance cochlear implant listening

Mark Fletcher, Institute of Sound and Vibration Research, University of Southampton

Over the last five years we have been looking at trying to improve outcomes for cochlear implant users by providing sound information that the cochlear implant struggles to provide through vibration on the wrists. But I'm going to start by telling you about some rumours that were swirling around in the 1920s about a young girl called Willetta. Willetta was a deaf and blind girl who could apparently read by feeling the ink on the page, smell colour, and – importantly for us – understand speech by feeling the vibrations. Seeing Willetta understand speech through vibration first-hand inspired Audiologist Robert Gault to team up with Bell Labs and produce a tactile device, called the Teletactor, which began to be used in some schools for the deaf in the 1930s.

But it wasn't until the 1980s that these "tactile aids" for hearing really started to take off. By the mid-1980s a new tactile aid, which was worn on the arm, was shown to allow users to learn a vocabulary of 250 words through vibration alone. But then came the cochlear implant and its remarkable success at restoring speech perception. It was so successful that by the late 1990s, the cochlear implant had all but wiped out the tactile aid.

Despite its success, the cochlear implant still has limitations. People with cochlear implants often struggle to understand speech when there is a lot of background noise and often have difficulties locating sounds. We wondered whether we could develop a modern tactile aid to fill in some of that sound information that the cochlear implant struggles to provide.

We first tested whether we could increase the percentage of words cochlear implant users are able to recognise in background noise by extracting key parts of the speech from the background noise and converting this to vibration on the wrists. We were very happy to find that even with little training our participants were able to recognise 10% more words on average with the vibration, and some recognised over 20% more. We are now working on improving how we extract the key parts of speech and how we deliver vibration so we can provide even bigger benefits.

The second thing we tried to improve was how well cochlear implant users could locate sounds. People with normal hearing locate a sound by comparing how loud



it is at each ear. If a sound is to the left, it will be louder in the left ear. This is because to reach the right ear, the sound must get through or around the head, which makes it quieter. For the same reason, if a sound is to your right, it will be louder in your right ear. We converted the sounds from behind each ear to vibration on each wrist, so that cochlear implant users could use this same process of comparing the ears with vibration. Because sound at each ear was converted to vibration on each wrist, if a sound was to the right, it would vibrate more strongly on the right wrist and if it was to the left would vibrate more strongly on the left wrist. By learning this rule, people were quickly able to locate sounds using our vibrations. Using this approach, cochlear implant users could locate sounds as well as hearing aid users, again with very little training. Like for our work with speech in noise, we are confident we can improve our approach to get even greater benefits.

We're also keen to investigate whether we can use this approach to enhance music perception and to improve general situation awareness - the knowledge of what and where things are around you. We're also seeking funding to build a device that takes what have been doing in the lab out into the real world, for people to use in their everyday lives. We hope to work closely with the NCIUA and its members as we build and optimise this device to maximize its effectiveness.

Artificial Intelligence and Cochlear Implants

Helen Cullington, Chair of BCIG and Professional Fellow of Southampton University

I know a lot about cochlear implants but I don't know an immense amount about artificial intelligence. However I am a very keen technology lover so I'm always trying to see how I can put new technology into what we do with cochlear implants.

So what is artificial intelligence? It is making a computer act more like a human, making a machine have human intelligence so that the machine can make decisions and act like a human would. Actually, it is incorporated into a lot of things we do and we don't even realise it. Google Map uses all sorts of different streams of intelligence to get someone to their destination. It analyses traffic patterns, the weather, news reports of any incidents and so on. Banks use it, Alexa, Netflix, Facebook – in fact we use a lot of artificial intelligence without even knowing it.

Artificial intelligence is used in healthcare more and more. For example, people with diabetes may be given a home monitor which will analyse their blood sugar patterns and looks for any significant change. If this happens it might get in touch with their doctor. It can measure people's retinas to see if they are normal or not and is much more efficient than a doctor as it has access to more information.

People often talk about the difference between data, information, knowledge and wisdom.

With regard to cochlear implants data may be collected by checking a cochlear implant user's electrodes in the cochlea, looking at their tuning levels overtime or even how often the person contacts the hospital, but all this data is not useful on its own, it's just a lot of numbers. We need wisdom, so we need the doctor, audiologist, speech and language therapist to look at all the information that is being presented to them to help them to make a decision about what is going to happen. I might look at somebody's electrode measurements overtime and see a change. This may trigger me to say to that patient you might want to come into the clinic. The idea is to use lots and lots of data to help people with implants to have a better experience and better outcomes.

If you are thinking about having a cochlear implant, as you all know, there are five stages: assessment to see if a cochlear implant would help, having the

operation, the mapping or tuning, the rehabilitation and then the ongoing life-long maintenance and checking of the equipment. When I asked you if you used artificial intelligence you could all put your hands up if you have a cochlear implant because your implant is already using it. The microphones are sampling the sound all the time and making a decision according to what environment you are in

and how to present the information to your implant. Most CI users are using artificial intelligence the whole time to hear better in different situations. We don't realise this is happening because it is happening hundreds of times per



second, all the time the processor is being worn. This is a really good example of AI being used to improve people's lives and it happens in hearing aids as well. A hearing aid and cochlear implant can be trained to pick out the sound you want hear from background noise.

Mapping and tuning is done by audiologists who may all manage things in different ways because they have been trained in different places and have different experiences. There are lots of complicated things with mapping and many adjustments can be made but can an audiologist think through the millions of possibilities and decide which is the best for you or would it be better to rely on a machine?

Artificial intelligence may also be used in predicting performance of, say, someone who has been deaf for a long time and hasn't used hearing aids, as it can access more data than the audiologist no matter how

many patients they have seen. Maybe in cochlear implant surgery computers will be able to help surgeons by allowing them to access information from more scans than they are able to look at. There is also the switch on. Perhaps this could be done gradually and automatically.

I hope this has given you a little snapshot into what is already happening and what is going to happen in the future but computers are not going to take over everything. There are still things that they cannot do. Don't worry – your clinicians are still there at your cochlear implant centre, ready to help you.

Manufacturer's News

From Advanced Bionics

Have you ever considered becoming an AB Community Mentor?

Advanced Bionics Community Mentors are a group of volunteers who support others on their cochlear implant journey by sharing their personal experiences. Hearing shared experiences from others on the same journey, is important when deciding if a cochlear implant is right for you or a family member.

Would you like to have fun, meet new people and be part of a supportive, friendly community? If you live in the midlands area (including East and West Midlands) and have or care for someone with an Advanced Bionics cochlear implant, we would be pleased to hear from you.

For an informal discussion, to learn more about AB, what mentoring involves and how to get involved, please contact us at hear-uk@advancedionics.com

*Full training is provided for anyone interested in joining the AB Community as a Mentor.

Hearing in Noise or Over Distance When Remote Wireless Microphones Deliver

Hearing aids and cochlear implants are life-changing solutions for people with hearing loss. But as many of those already using these devices know, there are frankly still situations where even these amazing technologies aren't enough to help them hear and understand speech.

When the noise in the room gets too loud, or when the speaker is far away on the other side of the classroom, people struggle even with the state-of-the-art cochlear implant or hearing aids. On our blog, CONNECTIONS, we spoke to Cecilia Zugaib – Roger Marketing Manager at Sonova – to learn more about why that is, and what we can do in those situations.

www. advanced bionics. com/com/en/home/contact-us/blog/articles/when-cochlear-implants-or-hearing-aids-arent-enough-zugaib.

From Cochlear

9/10 recipients would recommend Cochlear Remote Check

In the last two years, Cochlear has introduced innovative new technology and services offering cochlear implant users greater convenience and flexibility. This includes Cochlear Remote Check, an at-home testing tool allowing you to complete a hearing review using a compatible Apple or Android device* without having to travel to the clinic.

To find out more about how users felt about Remote Check, Cochlear ran a short survey. If you were one of the 100 survey responders, then a big thank you!

Here are some of the findings:

- 97% of respondents felt very or somewhat confident to complete their hearing check remotely¹.
- 92% were likely to use it again1.

"Technology helped to monitor my ability to hear without the need to visit the clinic" – Kenneth B. "Doing it from home I'm not tied to a set appointment, and any queries the team [can] contact me" – Daphne R.

9/10 respondents would recommend Remote Check to another recipient1 so why not try it for your next routine hearing check? All you need is a Nucleus® 7 or Nucleus® Kanso® 2 sound processor and the Nucleus Smart App on a compatible mobile device*. Check with your clinician if Remote Check is an option for you.

¹Source: Survey conducted by Cochlear on 102 recipients in January 2022.

*The Cochlear Nucleus 7 and Kanso 2 sound processors are compatible with Apple and Android devices. For compatibility information visit www. cochlear.com/compatibility.

From MED-EL

Reliable Hearing by Design: MED-EL Cochlear Implants

Since the very beginning, our life-changing devices have been developed with a complete 360-degree view of cochlear implant reliability and safety in mind. It's not only about making our cochlear implants and audio processors as reliable as possible: Electrode design, safe stimulation, and MRI safety* are also essential for all-round cochlear implant safety. Without considering these aspects, creating a safe and reliable hearing experience just isn't possible.

The Value of a Reliable Implant

Choosing a cochlear implant can be a decision for life. With a MED-EL cochlear implant, you'll have hearing you can always count on. Higher implant reliability can lead to a lower risk of additional surgery and higher satisfaction.

The Cumulative Survival Rate (CSR) is one measure of how reliable each implant model is over time. For example, a CSR of 99% within seven years means that the probability (as

demonstrated by experience) of a

cochlear implant providing continued benefits up to seven years is 99%.

99.98% CSR within 2 years

Leading in Cochlear Implant Reliability

All our latest-generation titanium implants have an overall cumulative survival rate of over 99% (as measured at the 2-year post-implant point), reliability performance that no other cochlear implant manufacturer has achieved. [1][2][3]

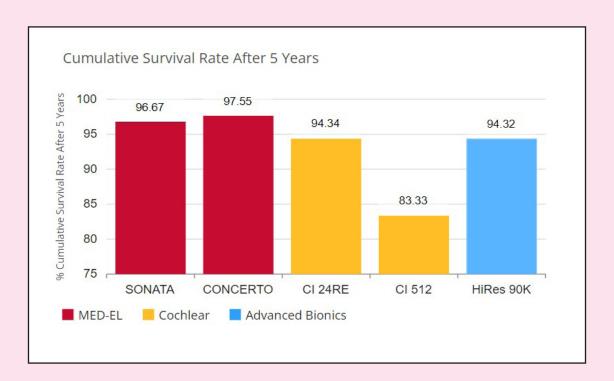
Reliable Cochlear Implants You Can Trust

Our newest-generation implant, SYNCHRONY 2, has one of the best cochlear implant reliability performance records on the market, with an overall CSR of 99.98% at two years. [1][2][3]

Reliable Cochlear Implants in the Long-Term

We know that manufacturers' reports alone don't always paint the whole picture. That's why it's important to look at independent data reported by clinics.

A recent study using data directly from clinics found that MED-EL's cochlear implants have a higher cumulative survival rate than implants from our competitors after five years.[4] According to this study, the probability that you'll continue to benefit from your cochlear implant after five years is highest with a cochlear implant from MED-EL.



Reliable Hearing You Can Trust

From the very beginning, MED-EL has been guided by our founders, the inventors of the modern micro-electronic multichannel cochlear implant. Our mission is to overcome hearing loss as a barrier to communication and quality of life.

Reliable Audio Processors

Our latest generation audio processors have a proven record of outstanding reliability too. In fact, the average monthly repair rate^[5] of all our audio processors is well under 1%.^[3]

RONDO 3 Reliability

With a single unit design, there is no need to replace cables or fiddle with opening the processor. This all-in-one design makes RONDO 3 both highly durable and user friendly for all ages.

0.16% Average Monthly Repair Rate

SONNET 2 Reliability

Released in 2019, SONNET 2 is our latest behind-the-ear audio processor. Made for the most natural hearing in any listening environment, SONNET 2 offers all-day comfort and wireless connectivity in a durable design.

To find out more information or to download a copy of our reliability report please visit our website: https://www.medel.com/en-gb/hearing-solutions/cochlear-implants/reliability#Audio_Processor_Reliability



- * MED-EL cochlear implants since 1994 are MR conditional. Recipients with a MED-EL cochlear implant may be safely MRI scanned following the conditions detailed in the instruction for use which can be found here: https://www.medel.com/en-gb/important-safety-information
- [1] Advanced Bionics AG and affiliates. (2021). Advanced Bionics Reliability Report Autumn 2021, 02-N258-02 Rev D.
- [2] Cochlear Ltd. (2021). Cochlear Nucleus System Reliability Report, Volume 10, December 2021, D1932780 V1 2022-03.
- [3] MED-EL. (2022). MED-EL Cochlear Implant Systems Reliability Report Spring 2022. All registered and currently marketed implants are included in the reliability calculations, and every explanted and returned implant is subject to systematic failure analysis. All failures are classified, and Cumulative Survival Rates (CSR) are calculated in accordance with ISO 5841-2:2014. All confirmed device malfunctions including accident-related failures are considered for reporting. Failures traced back to induced malfunctions are not included in the reported data in compliance with the ISO standard. The results of the calculations are reported following principles of the European Consensus on Cochlear Implant Failures and Explanations, with adults and children being shown separately and with 95% confidence intervals. Please be aware that confidence intervals smaller than 0.1% may not be clearly visible in the graphs. The sample size of each model and population are not provided. MED-EL publishes reliability data one year after the first implantation at the earliest.
- [4] Kim, S., Kim, M., Chung, W., Cho, Y., Hong, S., & Moon, I. (2020). Evaluating Reasons for Revision Surgery and Device Failure Rates in Patients Who Underwent Cochlear Implantation Surgery. JAMA Otolaryngology–Head & Neck Surgery, 146(5), 414. doi: 10.1001/jamaoto.2020.0030
- [5] The Monthly Repair Rate is a percentage that indicates the total number of audio processors returned in a month compared to the total number sold by the end of that

Improving Access to Cochlear Implants and Lifelong Services

Sue Archbold, Co-ordinator of Cochlear Implant International Community of Action (CIICA)

I am going to talk today about improving access to cochlear implantation and the life-long services required. People do not recognise the impact of hearing loss and they neither do they recognise what the latest hearing aids or cochlear implants can do. I am now very much involved in advocacy about hearing loss globally, and have been working with the World Health Organisation. In 2021 WHO launched the first World Report on Hearing. The department involved in hearing there has really grown over the past few years — do look at the website. https://www.who.int/health-topics/hearing-loss.

The World Hearing Forum (WHO) is a group of organisations dealing with hearing loss and deafness right round the world and it is open to organisations to join. The WHO website regarding hearing loss lots of information about the impact of hearing loss, how to fight for funding, how to check for hearing loss and so on. WHO says one in five people experience disabling hearing loss and for the over seventies it is the number one cause of years lost with disability. Hearing loss in adults is underestimated People with hearing loss are at greater risk of depression, cognitive decline, falls, other health issues, unemployment and underemployment and there is a lot of evidence about this. The diagnosis of deafness brings a change to people's self-concept, particularly if you go deaf suddenly. It is psychologically difficult to accept; it can leave you feeling isolated.

Last year WHO reported that cochlear implants are one of the most successful of all neural prostheses. This was a strong statement for WHO. However, access to CI is low and provision very patchy in the UK and globally. Only one in twenty who could benefit from a cochlear implant receive one and even in high income countries there is considerable variation in provision for an implant and for the following services.

Why are people not getting a cochlear implant? For many people with a severe or profound hearing loss referral for a cochlear implant is not mentioned. The lack of awareness of the understanding of hearing loss is demonstrated in the amount per year spent on research in the UK. In 2018 £193 was spent on cancer research for every person affected by cancer, £21 was spent on cardiovascular research for every person affected and £16 was spent on vision. With regard to hearing loss it was only 83p per person affected by it. Deafness is an invisible disability and therefore loses out in research funding.

There was a major survey in Germany to find out how many people knew about cochlear implants but it revealed that 69% of the German population had never



heard about cochlear implants. Then hearing aid users with severe to profound hearing loss were asked if they had been informed by a medical professional about cochlear implants but only 18% said that they had in spite of the fact that cochlear implants have been around for a long time. Got to www.ehima.com for the full reports. Even if people do go further and look at the possibility of having an implant there are still problems because information about them is often not readily available. Research in the States gave several reasons for people deciding not to go forward with a cochlear implant: they were concerned that it would not improve their communication ability, they were concerned about the risks of surgery and their post operative recovery.

We did manage to get a growth in cochlear implant provision for adults in the UK. An action group for adults with cochlear implants was established, and developed a series of reports that could be used by politicians and were launched at a conference in Westminster. The message was that cochlear implants, although expensive, actually saved society money because they changed people's lives. NICE has listened to many of these arguments and the guidelines were changed, as you know. The pandemic affected all our lives and the NHS has huge backlogs but we still need to ensure that hearing loss keeps at the top of the health agenda;

it affects so many people.

We did a global consultation asking people about the worst barriers to implantation in their countries. It turned out that the top three barriers to access to implants globally was lack of awareness of the impact of hearing loss, lack of referral pathways and lack of funding. Advocacy work, especially by user groups, is important as the politicians and governments tend to be more likely to listen to them. If you ask people why they decided to have a cochlear implant it is more often because they have met someone who has one and have seen what they get out of it.

If you are going to build advocacy work to make an impression on governments and international organisations you need a network of organisations to get a digital platform where they can share resources and inspire each other. The Cochlear Implant International Community of Action (CIICA) of which NCUIA is a member, was formed after the consultation asking groups what they needed. CIICA now involves 52 countries with 80 global organisations and over 400 members so it is very active in the world and has an extremely active website. People doing advocacy work need the tools to affect the change such as the synopsis of all the information in the 250 page long WHO report. So far there have been 2,500 downloads from the website; our website has 40 languages available. CIICA members not only do advocacy work but, with the help of organisations like EURO-CIU, co-ordinate some practical work such as getting batteries and leads to countries which find it hard to get supplies, like the Ukraine and their refugees.

CIICA has also worked to educate people about the importance of hearing well for healthy aging. Too often people are screened for everything except hearing loss. In care homes it may be that people are diagnosed as having cognitive decline when in fact what they really needed was a hearing aid. On the website people have been sharing advocacy ideas – in Spain they have been pretty active and in Madrid buses have signs up about the impact of hearing loss. CIICA also has live events where people can listen to each other and have conversations about specific topics. Zoom with captioning means that these can be accessed in almost any language. In the chat room people can talk to each other and share experiences. Do have a look on the website: www. ciicanet.org

At CIICA we have just done a survey of adult CI users globally to find out what services they get and after getting an implant what else they would like. There were 1,222 responses from 40 countries, which was amazing, and thanks to NCIUA for all those who completed it. If you go to www.ciicanet.org/news you will find some of the first responses. The free responses which are so interesting are currently been analysed.

Advocacy works when there is real leadership and a plan so do have a look at the CIICA website and remember you can join as an individual and receive regular updates on the work our members are doing, and you can join the Conversations and Events.

BCIG Annual Meeting, Cardiff 26-27 April 2022.

The Association has for many years been a subscribing member of the British Cochlear Implant Group. Each year BCIG holds an annual conference, usually hosted by one of the UK CI Centres. It brings together the professionals working in the field with representatives of the CI manufacturers in a way which is more or less unique in the world, and the Association aims to be represented where possible.

In 2020 the conference was held at Nottingham in March as the pandemic was gathering momentum, and in retrospect we were very fortunate to have been able to squeeze in a physical meeting just before lockdown started. For 2021 an online event was organised, which I logged into on behalf of the Association: from a technology perspective it filled a need, but lacked the immediacy and opportunity for informal interaction of an in the flesh meeting. So everyone was delighted to be able to meet up

again in April, with Cardiff's Edwardian City Hall as the venue. This allowed Nigel Williams to attend several sessions, alongside Tricia Kemp and myself. In parallel with the main sessions there was also a Cochlear Implant Champion Scheme event running in an adjacent room: the role of Champions is to reach out to local audiology clinics and ensure that they are fully aware of the benefits an implant can give their patients, and are confident operating the selection criteria as approved by NICE.

The event started with something of shock, with the head of Cochlear UK announcing that Oticon had decided to withdraw from the CI market, and that heads of agreement had just been signed under which Cochlear would provide future support for Oticon's user base of about 75,000 patients around the world.

What would have been the Oticon technical presentation later in the Conference was used in part to explain that when they decided to enter the CI market Oticon understood that they would have to trade at a loss for a couple of years whilst they established a position in the market, however the enforced hibernation of so many of the world's CI Centres during the pandemic had made it impractical for them to establish themselves in a realistic timescale, hence their decision to withdraw from the CI sector of the market. They had also experienced some early failures with their Neuro Zti implant, and although the failure rate had been very low they had nevertheless opted to voluntarily withdraw the device from the market, which had added to their problems.

The presentations to the main conference were of the usual high standard, featuring several invited speakers from outside the UK alongside contributions from many of the UK Centres.

Catherine Birman who is the consultant surgeon on charge of Australia's largest CI programme gave this year's Graham Fraser Memorial lecture entitled "optimising outcomes in cochlear implants. Her recommended way forward was by offering as personalised an approach as possible, and by focussing on driving up the results experienced by patients in the lower quartile. Professor Marco Caversaccio of the University of Bern gave an

overview of work ongoing to use robots to perform CI surgery, with the objectives of reducing cost and maximising consistency of approach. As of today there are several promising trials in progress around the world, though the finished product isn't there yet. Louise Craddock of the Midlands Hearing Implant Programme gave an update on behalf of the group revising the BCIG Quality Standards – on which the Association has already made comments. Enrique Lopez-Poveda of the University of Salamanca talked on "Binaural audio processing for better hearing in noise". The key message was that with bilateral implants the brain can lock onto the sound from the ear which has the better signal-to-noise ratio. This isn't an entirely new hypothesis, but it was useful to see some evidence to back it up.

Overall the event featured around 30 formal presentations, supported by a set of 82 "Poster presentations" in which people doing relatively small scale research projects within the UK Centres were able to share the results of their work with the wider CI community. It is comforting to know that such a huge amount of work is going on to improve the patient experience, and that the Association is able to have visibility of it.

Paul Tomlinson

Communication

In this online world of today, communication by email is increasingly important not only for simplicity and no cost but also to avoid postal delays and strikes. Some members may not have received the email notice about the Technology Day at Cambridge and this note is to ask all members to please check if they have registered their email address with our Secretary (secretary.nciua.org.uk) and if not to do so now please."

NCIUA Technology Day, 11am, 12 November, 2022

This will be held in conjunction with the Cambridge CI Support Group at MRC Cognition& Brain Sciences Unit, 15 Chaucer Road, Cambridge CB2 7EF

For further information see our website at https://www.nciua.org.uk/event/nciua-technology-day-saturday-12-november-2022

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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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