CIICA Conversation: ADULTS WITH CI: NOBODY TOLD ME WHAT TO ASK...

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Facilitators: Kris English, Prof Audiology, USA

Michelle Frisbie: Bilateral Implants, Treasurer, HLAA state & local chapters, Wisconsin, USA

Emma McAuley: CI user, Audiologist, Ireland.

21 Attendees from 10 countries: 11 users of CI; 3 audiologists (2 of whom also CI users), 2 waiting for CI, one person with sudden hearing loss. Live captioning was provided. Participants were from Belgium, Canada, Finland, Ireland, Romania, Slovenia, Switzerland, Turkey, UK and USA.

Introductions:

Kris welcomed everyone, provided some housekeeping notes, and encouraged attendees to introduce themselves via the chat room. She reminded everyone that the meeting was not recorded but a summary, based on the transcript, would be shared and would contain anonymised quotes.

Framing the Conversation

Kris began by reminding participants that these issues had been brought up during several previous conversations:

- "There needs to be a way to empower recipients to know what questions to ask – a resource with what things you need to ask about."
- "Someone needs to develop a guide for adults going for CI before their first assessment."

Relying on internet searches can be problematic: even when you know what to ask, most websites do not meet readability criteria. Kris pointed to a recent study looking at how people used Google to learn about cochlear implantation:

They noticed that 80% of the websites they were looking at far exceeded what would be standard readability levels for persons who don't have much background but want information. The websites are helpful but they are not actually written by persons who lived the journey.

(Benaim et al. [2025]. What do people want to know about cochlear implants: A Google analytic study. *Laryngoscope*, *135*, 840-847.)

This Conversation was to begin the process of developing a readable guide representing input from CI users. She thanked those who had contributed their questions already, including these sent by Mary Anne, who wished she had asked before CI:

1. Exactly how rehab would be provided
2. Available support services to learn how to use assistive devices
3. How to determine if hearing problems are device-related

Michelle then went on to share these questions:

- How to select among CI brands
- Assess potential balance issues
- Complete info re: bilateral implants
- Importance of early, continuous AR

Choice of device

Michelle commented that she had no choice of device when she had received her first implant, and that there was much more information now – perhaps too much.

I can imagine how overwhelming it must be today to try and decide. We'll hear from other people today, maybe how they have decided. I know there is a chart out there that compares all three devices, that is very in-depth and a wonderful resource.

(The chart can be found at the end of this summary.)

Balance issues

Michelle then brought up balance issues, and whether balance testing is done prior to CI:

I believe now they are doing balance testing before first and/or second implants, which is wonderful to hear. I have had a few vertigo issues after I got the second implant. I wish I would have known about balance issues prior so they could do testing and see if I would be more susceptible.

This raised a lot of other comments, including:

The balance testing that Michelle mentioned would be really useful. I suffered a lot with my balance after I had my cochlear implant. But I didn't have my balance assessment until about a year after when I couldn't walk because I was quite badly affected.

In my case, I was implanted first time 11 years ago. I had no balance testing whatsoever. I find that kind of funny that no-one ever asked about or did anything to test my balance.

An experienced audiologist commented that most centres don't do balance testing but she thought it was a really good issue to follow up.

Bilateral CI

The next issue which Michelle raised was about the benefit of bilateral CI: this was unusual when she had her first CI:

When I first got implanted there were not that many people having a second implant at that time. I was doing as good as could be expected with my first, so I didn't really consider the second side until

10, 15 years later when I started hearing from others that they were getting benefits from bilateral. I started to think about the safety issues for not being ability to localise sound when I was out biking or hiking, things like that.

Other participants commented on the length of time between 2 implants:

I also wish I would have considered the second side sooner. I think my second side is not as good as my first side because there was such a span in between. Some research out there says you may not be as successful the longer your ear is not receiving any sound or stimulation, it is good to get that ear stimulated.

My second implant was only a year after the first one. The first one was really great; after about six months I was understanding practically everything so I got the second side done. Over time the second side was the better side and the original side not so good.

I went into it with no expectations as to whether it would be better or worse. I said, OK, the left side was good. Let's see what happens when I get the right side done. Over time I was surprised because my left side had been so good and now it's not as good as it was. Maybe I get 60, 70% of what I understand in my left side.

The consensus was that a second implant was rarely mentioned by CI programmes, and participants wished they had heard about it sooner:

I wish somebody would have said something and recommended it sooner. I definitely do feel benefit from the second side... If I don't put the second side in when I go to a grocery store or a meeting, I cannot hear. I know I miss it. Yeah, I just wish somebody would have said something sooner.

An audiologist commented on bilaterals and mentioned that they are funded in Turkey:

But we try to tell them about why bilateral cochlear implant is important. How beneficial for them. In Turkey the Government funds bilateral cochlear implants, but we needed to ask the Government, we needed to explain why the patient needs bilateral cochlear implant and after that the Government funded it.

There were comments as to whether it was possible to have 2 different implant systems:

Actually this does happen. It's not desirable, in my opinion, but some people do have mixed brands. I would think, in terms of balance of hearing, it's better to have the same on both ears. But this is not a question necessarily that occurs to people when they are in the clinics.

The Benefits of Aural Rehabilitation

There was a discussion about the benefits:

I wish I knew what I know now -- and I still need to get myself better at aural rehabilitation. That was not even heard of 25, 23 years ago when I got my first implant, or it was not used in that terminology. There were no resources or people available to do the AR training.

For Turkey, it was mentioned that:

The Government also have funded rehabilitation. In Turkey, most of the adults don't want to use the rehabilitation options. So maybe we do not explain enough the importance of the rehabilitation after cochlear implantation. We are talking with their sponsors, their children or the adults about why cochlear implant surgery only is not enough, they need aural rehabilitation after the surgery.

A discussion took place about various approaches to rehabilitation for adults as a result of this question:

In my country, the rehabilitationist always says that a speaker should cover their lips and we should try to understand the voice, but it is something impossible for me. What do you think about that?

It was pointed out that this approach is intended for formal listening practice, not "real life." The discussion summarised that it can be helpful to concentrate on listening alone, but human communication usually involves the whole person in communication including lip and face reading. Many people do become able over time to understand without lip reading but for most, in noise for example, lipreading is important. One participant noted that his wife would read sentences from a paper but cover her mouth and he found it helpful to concentrate on listening.

A lot of the rehab I have done online, some programs would give you a choice of watching a face or not. Then background noise is added. Early on it is good to focus on what you are hearing and practice that. But no-one should say you can only do it one way.

Another participant commented that visual cues are helpful when you are tired:

Listening through a cochlear implant can be very, very tiring. And the more tired you are, the more you are going to resort to going back to using visual cues to help you to listen. If the expectation is that, once you got your CI, you should be able to hear everything all the time without visual cues – that is completely unrealistic.

Emma had found Bluetooth support for rehab invaluable and it hadn't been mentioned:

Bluetooth and rehabilitation, that is a huge plus. My CI clinicians talked about reading books while listening to the audio books. I was thinking, when am I going to get the time to sit down and listen to an audio book? I found that once my CI was connected to my phone, I could listen to the news on the radio, and then the chat shows and the debates. This is every day, general conversation with accents from Dublin, all round Ireland, that was very helpful for me.

Music was mentioned by several as important in rehabilitation and wasn't often discussed beforehand; for example:

I heard people saying, don't bother, you'll never really hear music again. But just yesterday I just listened to Brad Ingrao -- he is an implanted musician and an audiologist. He talks about cochlear implants and our expectations with music. Bob Goldsworthy is doing great work over at USC, inventing new tests, new ways of trying to see how people can improve their perception. For the longest time I could not hear notes in a chord. I just would hear, maybe one dominant note or, but I couldn't distinguish between notes and the chord. Well, I am starting to do that now. The plasticity of the human brain is important and there are several really great books which have come out about how the brain perceives sound. I just want to enjoy music! Even if we were not professional musicians, even if it is not the same as before ... you are not going to hear it the same way. But over time you can, if you love music you can find pathways to enjoy it.

Emma's contributions

Kris then introduced Emma, an audiologist and CI user who described questions she wish she been told to ask about:

- Post-op sore throat
- Keeping bandage from slipping off while sleeping

- How to meet other CI users
- How Bluetooth supports listening practice

Emma reported on the value of being well prepared and felt that she was given lots of information:

I only have one CI because adults in Ireland are only offered one at the moment. I am still getting benefit from my hearing aid in my other ear. I think if I lost my hearing in my hearing aid ear, I suppose I would like the option of having a second CI. I was given a lot of information on what to expect, and what issues might occur: I might have tinnitus afterwards; my balance and sense of taste might be affected – maybe to lower expectations. They kept checking in with me on what my expectations were. I wasn't able to bring family to my meetings but that was because I was implanted in December '21 – we were in the middle of the COVID pandemic. What I wasn't told about was that I might have a very sore throat, which was more annoying for me than the ache on the head.

Emma had, however, been given a lot of practical tips:

I was told to bring in a spare pair of glasses and take off one lens and one arm on the side where the surgery would be, because that side would be sore or tender and probably bandaged. That was a good point that I never thought of myself.

The bandage kept slipping off my head. I think a couple of times during the night, nurses came up and tightened it up again.

Meeting up with others:

As an audiologist, Emma had been able to meet CI users beforehand, and felt it was important:

I met a few other CI people, people that I knew before I had my implant through my own work as an audiologist and also mixing in the hard of hearing community over the last 20 years, so I talked to them for tips of what to expect. But I was not given any names by the hospital to reach out to.

Others also found peer support invaluable:

Peer support is important. There are a few people coming to one of our hard of hearing groups in Dublin now who are on that journey, that CI journey and they are not fully made up their mind yet but they want to talk to other people.

I wish the professionals would provide more information about peer support. Sometimes we get frustrated that we end up learning this stuff from our peers. Yes, the peer support is amazing. We need that also. But I don't want to let the professionals off the hook. I think it is important for them to expand their paperwork and information that they share with their patients also. They should be telling people about HHLA. The American Cochlear Alliance. The Facebook cochlear implant group is phenomenal.

Advice about when you would be able to hear.

One participant mentioned that they would have liked more information about when they would be able to hear with CI:

How long is that process? No-one explained about it. OK, you will get a cochlear implant. Perfect. Then you will hear, perfect. But I didn't hear and that was very stressful for me. Usually they said, people with progressive hearing loss are able to hear immediately. I didn't. That was a shock for me.

And I didn't have any support during that time in the hospital. I've organised a support group in Slovenia now.

She commented that the week before the processors were fitted were really stressful with no hearing.

But that first week was very, very stressful for me. I relied on my hearing all my life... and so, that was really stressful.

Family involvement by the CI team:

This was considered to be important by users, but rarely happened:

Another thing is that there is no support for family. I was at that time a mum with three children and I needed to explain everything to them about cochlear implants. No one was thinking about the family, especially about children living with us. I think this is very important issue for everybody.

Before closing, Kris brought up two questions previously suggested for a resource guide, and asked the group if they agreed they should be included:

- does your programme have experienced cochlear implant users I could meet?
- does your centre include counselling support for me and my family?

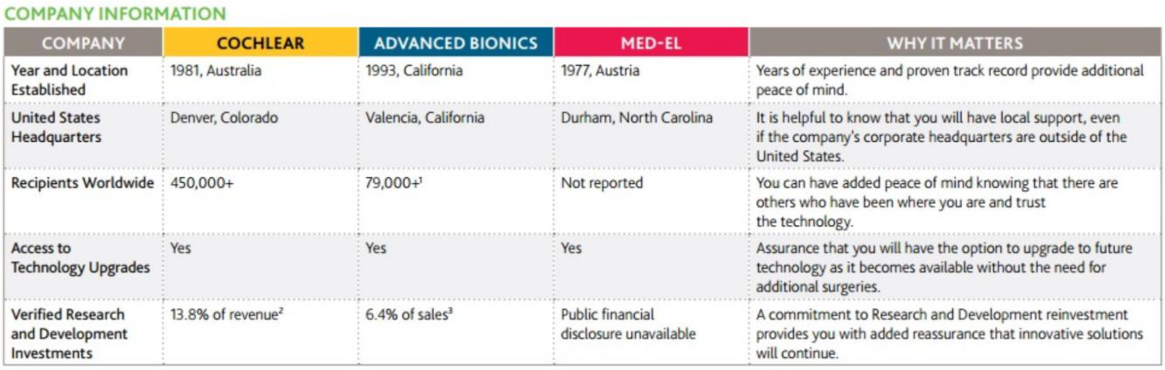
All agreed with these, and other suggestions were made:

- ask about the impact a CI may have on other existing health issues
- ask whether CI would have an impact on tinnitus

Conclusion

A whole range of issues came up in this Conversation which will help in developing the next stage of the guide. Thanks to all who took part, and we look forward to sharing and piloting the questions.

Kris English, Michelle Frisbie, Emma McAuley, Sue Archbold, CIICA, May 2025



COMPANY INFORMATION

COMPANY	COCHLEAR	ADVANCED BIONICS	MED-EL	WHY IT MATTERS
Year and Location Established	1981, Australia	1993, California	1977, Austria	Years of experience and proven track record provide additional peace of mind.
United States Headquarters	Denver, Colorado	Valencia, California	Durham, North Carolina	It is helpful to know that you will have local support, even if the company's corporate headquarters are outside of the United States.
Recipients Worldwide	450,000+	79,000+[1]	Not reported	You can have added peace of mind knowing that there are others who have been where you are and trust the technology.
Access to Technology Upgrades	Yes	Yes	Yes	Assurance that you will have the option to upgrade to future technology as it becomes available without the need for additional surgeries.
Verified Research and Development Investments	13.8% of revenue[2]	6.4% of sales[3]	Public financial disclosure unavailable	A commitment to Research and Development reinvestment provides you with added reassurance that innovative solutions will continue.

https://hearandnow.cochlear.com/hearing-solutions/services/resource-to-help-you-compare-cochlear-implant-devices/)