CIICA Conversation:
ADULTS WITH CI: ACCESSIBLE BILATERAL COCHLEAR IMPLANTATION
15 April 2025: Summary of the conversation

Facilitators:
Manohar Bance, CI Surgeon, Cambridge UK, Wendy Huinck, Associate Prof ENT, Nijmegen, Netherlands, Robert Mandara, bilateral CI User, Finland, Anne Marie Langlois, Bilateral user, Canada.

17 Attendees from 6 countries: 8 users of CI, and a range of professionals, including surgeons, audiologists, therapists, and from industry. Live captioning was provided. Participants were from Belgium, Canada, Finland, Netherlands, UK and USA.

Introductions:

Sue welcomed everyone, provided some Housekeeping notes and encouraged attendees to also introduce themselves and via the chat room, and mentioned that there would be no recording but be a summary, and any quotations used would be anonymous, before handing over to Manohar as facilitator for the event.

Framing the Conversation

Manohar set the scene reminding everyone of the question What Can you do with 2 implants that you couldn't do with one? Which was the title of the Conversation. He began by suggesting that participants consider the following questions while listening to Wendy:

What is it in your daily life in your lived experience that the second implant gives you in your daily life that you don't get with one? And I see it really in sort of 3 different segments:

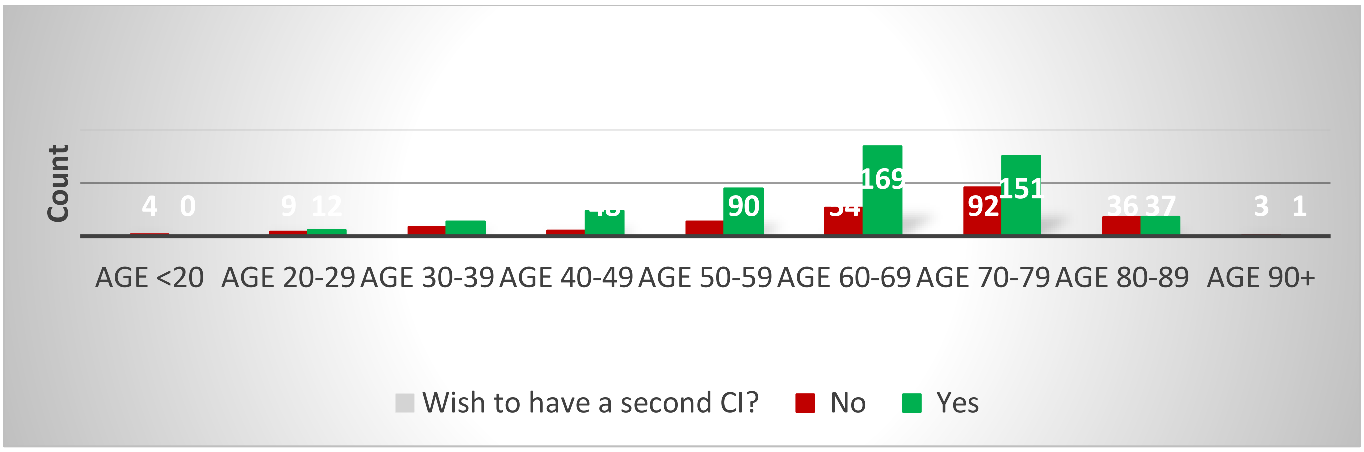
The first is: Why did you want a second implant? For those who have had it sequentially what did you think you were missing that you thought the second implant would give you?

Then when you got it, what did it give you that you didn't have with the first implant? So what incremental value did it bring to your life?

And the third part is if you have bilateral implants, if you take one off for whatever reason if it breaks, you have to go with one, what do you miss? What is it you can't do any more when you only have one implant you can do when you have both of them on?

He then introduced Wendy Huinck from Njimegen CI team to discuss the survey they developed to have a better idea of how many people do want a second implant, which isn't funded in the Netherlands. They had almost 800 respondents and it was posted on the Dutch patient organisation websites.

Do you wish to have a second CI? Results in the slide and you see that still quite some people do not want a second implant.



She then explained that they had asked the reasons to choose to have a second implant, and then the main reasons given were to improve directional hearing, to improve speech perception and to improve speech perception in noise.

Looking at the reasons given why people do not want to have a second implant, there were a range of reasons given. which Wendy clarified:

Most of them who don't want a second implant they say: "I am just satisfied with one implant" and yes, I think that's a very good reason. But also "I benefit from the hearing aid in the other ear" and that's what we see quite a lot in the Netherlands because we do have people with quite some residual hearing, and then the acoustic sound is also beneficial of course. For some people it's just not possible for several reasons. Some people think "I am too old", "I find it too burdensome", and for some the result of the first one had been disappointing.

The Canadian CI campaign

This survey was really helpful to think about some of the issues, and Manohar went on to introduce Anne Marie Langlois, from Canadian Hard of Hearing Association (CHHA) who began by describing the CI campaign developed across all Canadian provinces, where funding varies, with the support of all CI industry, and stimulated by the Spend2Save initiative begun by Brian Lamb and Sue Archbold. The campaign has as one of its aims the funding of bilateral CI for adults.

The approach is both national and provincial and our current focus is launching a website, but also the development of a national report card which will grade but that has yet to be established what the criteria will be. The committee will be talking about that actually this month, but will grade provinces on their provision of CIs; criteria that might be included or funding that's available, as well as ongoing support pre, during and then post-surgery.

We will be building advocacy; we also are engaging ambassadors to assist us.

Anne Marie then went on to describe her experience of the second CI:

My first CI I got in March of 2023, and my second CI in February of 2024, I am happy to report that at my one year assessment for my left side, which was my second, I scored a hundred per cent. And my left side has actually surpassed my right with respect to results, both in crowded environments, noisy environments and in quiet environments, words and phrases. So quite surprising.

What changes had she noticed? Anne Marie had noticed changes quickly:

I would say probably a month or two …In fact I just had an adjustment to both in February, and I need an adjustment again; my brain is hungry for sound

She then raised a number of changes she had noticed, and others commented further. Sound localisation was greatly improved for Anne Marie and others:

So improved direction and sound detection for sure is off the charts.

Another participant commented on improved localisation and its impact:

After 19 years Toronto allowed for a second implant, so the change with the second implant was the balance of sound coming at you, everything was always in my right ear before and when I got my second implant I could bring the sound down in my right one and increase it in my left one so you know when the noise is coming from the left or if it's coming from the right, so you are not constantly always turning to the right. So I found that was a huge improvement and when you are sitting at a table or in a noisy restaurant, you don't have to put yourself at the end of the table because you only had one CI, you now have two. So you can listen to all those people talking to you on the left and people talking to you on the right, and it's not like you have to keep moving your head left and right to try and follow the conversation.

And from another participant:

I started with one in 2007. I had a progressive hearing loss that didn't start until my teens. I thought I was doing OK keeping life on one side of my head, and then I got my second one in 2011 and it's so much easier to have sound on two sides again and the biggest thing for me was like the world is in 3D again suddenly I could hear leaves scattering on the sidewalk in the wind, I just feel much more grounded in my environment and in my life and so it's easier to move through it with more confidence now.

And another :

My speech perception is great. It's just a world's difference and a vast improvement,

A reduced need for captioning was reported.

I relied heavily on closed captioning prior to CIs, but also I needed it still with my first CI. I did have a hearing aid in the other ear. I still did have difficulty particularly with unfamiliar voices, accents, things like that. Now (after the second) I am contemplating not renewing my captioning subscription, because I don't need it any more at all.

Phone calls were reported to be easier with the second implant,

Phone calls was another thing. My work as a consultant - I don't have to worry about phone calls now

Before getting bilateral I was still absolutely terrified of using a telephone. now I don't care. I can just stream calls, it's easy.

Tinnitus had disappeared with the second implant for Anne Marie:

My tinnitus went away completely. So with hearing aids I still had tinnitus. With one CI I still, I did notice a reduction but it was still there. It has gone completely when I wear them, so not surprisingly I wear my processors from the moment I wake up until the moment I go to sleep.

Music emerged as a positive experience:

I think one piece that has really made a difference for me is music. We all know I think, those of us who have CIs, how the acclimating period with music takes much longer than speech. And it wasn't until I got my second CI that music started to sound better - it's still not a hundred per cent yet. But I am able to recognise songs now, whereas with one I still really struggled; It didn't matter if the singer was male or female. Now I can actually make out male and female voices and I can detect certain instruments again.

Anne Marie commented that others reported that her speech had improved:

The other piece for me that others have commented on - not my immediate family, oddly enough - but everyone that I have encountered, I think I am up to about two dozen people because I am keeping a tally in my head of people who have said my voice has changed completely.

With improved confidence, several reported increased independence, and reduction in stress, for example when travelling:

travelling independently and stress free travel. My anxiousness when I used to travel, particularly airline travel but even border crossing, was so high, so high, it was awful and I was very much dependent on my husband. I am proud to say that my last trip, my husband felt confident enough I suppose, or I felt confident enough, he went off to the bathroom and there was an overhead announcement and I made out all of it. All of it. I was able to understand the pilot because of course on airlines again there's no transcription of announcements. My stress level has gone down significantly.

For another participant:

I identify with so much with what Anne Marie said about the stress and travelling in particular and I have actually missed a flight because I missed announcements before pre-implantation and I thought, I thought I was doing well with one implant

The reduction of dependence on others was picked up:

and then also I think Anne Marie said about the reliance on other people, on her husband for listening to announcements, it's absolutely true.

The ability to take phone calls increased independence:

Before getting bilateral I was still absolutely terrified of using a telephone. I would do anything to avoid using a telephone and would get my wife to make all the calls and now I don't care. I can just stream calls, it's easy. It's such a relief.

The ability to do two things at once could be helpful in real life:

The one thing that I really enjoy too is when I am watching TV. I can listen to music and I can stream on one ear and have the TV or the music coming in on one ear, but I turn it down on my opposite ear. So if my husband is in the room and he is talking to me I can still chat with him while listening to the TV or the news or music in my other ear.

: Yes, if I can comment. One of the things I have noticed with work in particular is I am able to multi-task far more on calls and that doesn't mean not pay attention. It means I can listen and not have to look at, you know, closed captioning and reading lips all at the same time. So if someone is looking for a document and I am supporting, like, Marilyn as an example for this Spend2Save committee, if they are looking for something and they mention it, I can go off and find it in the files, send it off to Marilyn and still keep up with what's going on. The same is true of note taking.

The reduction in listening fatigue was a topic that resonated with participants:

But yeah, yes, so with two CIs, yes, I find it's - you're not as tired at the end of the day. One CI was great. I loved it. I used it for 19 years and I made do with it, but once I got the second one it's like, OK, you don't have to be on the look-out as much any more as who's talking to you if they are on the side where you don't have the implant.

My work is HR, and I am talking to people all day long. And yes, I would come home absolutely exhausted. So I don't have that exhaustion

This is something that's really difficult to measure but the listening effort is so much less with two implants that we are not so tired. We've got more energy to do things and this is a really difficult thing to measure.

Tinnitus had disappeared with the second implant for Anne Marie:

My tinnitus went away completely. So with hearing aids I still had tinnitus. With one CI I still, I did notice a reduction but it was still there. It has gone completely when I wear them, so not surprisingly I wear my processors from the moment I wake up until the moment I go to sleep.

Participants were asked about the experience of having the second one, and how it differed to the first one. The consensus seemed to be that it was rather different in several ways:

when it comes to the second one you think OK, I know what the surgery is like and I know what rehabilitation is like. But actually I didn't understand anything on the second ear for quite some time either. I just thought it would be faster because I knew what to expect and it wasn't.

However for others it was faster:

finally in Ontario they allowed the second CI and I went into the office and I took my first, my 19 year old one off and I was able to hear right away with my new (second) CI; so everybody is different. And that's what makes us all unique because we all have different experiences. So my left ear was always my better ear, but I never used it for 19 years and I had my worst ear (right) operated on in the beginning because I didn't think it was going to work. So when I was in the audiologist's office and I was hooked up with my left ear, she had me remove my right CI and she covered her mouth and started saying things in sentences and words to me and my brain was ready to go and I was one of the luckier ones, but my second CI went very well. To this day, if I do get a little tired or something, I will pull my right one off and I will just listen with my second one, with my newer one because it just, it just keeps it working harder too because my 19 year old one has 19 years on my left ear, so trying to balance it out a bit. But yes, so we are all different.

Some shared concerns re the second surgery; for example, that it would destroy any residual hearing:

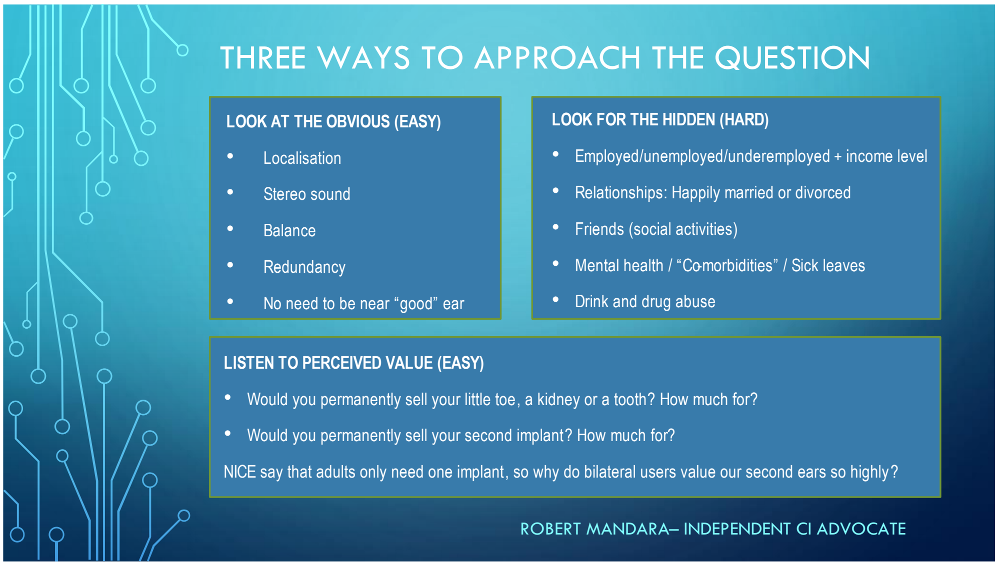
With the second one I found myself more anxious and when I dug into why, it was that I was going to be completely deaf. And what did that mean? I had to dig into that a little bit and think about it caused what caused a little bit of trepidation and it was identity. So, you know, I am hard-of-hearing when II have my CIs on. I am completely deaf when I don't have my processors on, and because I have worked with individuals from the big D Deaf Community, you know, often times identity can be a tricky subject. And so that was the one piece that I had a bit of trepidation about, but that's it. I am so over that now. I tell people when I have them on I am hearing and when I have them off I am Deaf.

Another concern was that now both ears may not be able to take advantage of newer technology:

. *It was a bit of a fear but partly because we don't know, none of us know what technology comes next and by getting the second implant we are basically ruling ourselves out of stem cell, gene therapy, or whatever might come, and my way of looking at this is that I am maybe in the final third of my life and it's not going to be my problem so much as for children born today that get bilateral implants; they are the ones that are going to potentially suffer, so I am quite happy to live as I am for the rest of my life. But we do have to be careful because, you know, we don't know when war is going to come or, you know, a brand goes bankrupt, that suddenly we are left deaf. That's slightly scary. But I don't think about it.*

and I am encouraged at being able to upgrade sound processors on the outside without messing with the inside, hopefully, for the rest of my life.

Robert shared this slide and looked at the question in three ways, illustrated here.



THREE WAYS TO APPROACH THE QUESTION

LOOK AT THE OBVIOUS (EASY)

- Localisation
- Stereo sound
- Balance
- Redundancy
- No need to be near "good" ear

LOOK FOR THE HIDDEN (HARD)

- Employed/unemployed/underemployed + income level
- Relationships: Happily married or divorced
- Friends (social activities)
- Mental health / "Co-morbidities" / Sick leaves
- Drink and drug abuse

LISTEN TO PERCEIVED VALUE (EASY)

- Would you permanently sell your little toe, a kidney or a tooth? How much for?
- Would you permanently sell your second implant? How much for?

NICE say that adults only need one implant, so why do bilateral users value our second ears so highly?

ROBERT MANDARA– INDEPENDENT CI ADVOCATE

We can think about the sum of all of the benefits and some of those are really easy to measure, so the obvious things we have been talking about are localisation, whether that's sounds coming from left or right, stereo sound appreciation and that might mean that, you know, you might hear which direction the car is going to hit you from, or in sport localisation could be really important to know whether the player is on your right or your left.

Stereo sound from music, balance, which simply feels more balanced.

Redundancy: With bilateral implants you obviously have some redundancy that if one device fails you can still go to work while the other one is being sorted out. That is really reassuring,

Another commented on the importance of redundancy :
And I was actually reminded recently how grateful I am to have two. I had one of my, I went in for re-mapping and one of my sound processors literally died in the audiologist's office. I needed new parts and I am in the United States so it took a couple of months to sort that out with insurance unfortunately, so then I was down to one again for all of last autumn actually, so it was a good reminder of all the reasons that I appreciate having two more. And kind of day-to-day things what's nice about having two is when your batteries die on one side, the whole world doesn't shut off all at once.

there's no need to always be walking on the right or left side of someone just because that's where your good ear is. I don't have to think about that at all. So all of those things are quite easy to measure.

But then there's the harder things to measure - and particularly to get the whole picture of somebody as an average - but, for example, I would wager that those with bilaterals are more likely to be employed rather than unemployed or under employed, and maybe their income levels would be higher, but it's difficult to measure.

If you think about personal relationships, I can say in my personal relationship I don't think my marriage *would have survived if I hadn't got CI, and my relationships are far better with bilateral CI and that's with family and friends.*

Social activities. I am far happier to go out and be with people without thinking Oh, I am not going to be able to hear. I don't really want to go. You know, and then in terms of mental health - I don't know how you measure it - but I think we all sort of agree we feel better; we are under less stress and I hate the word "co-morbidities", but if you look at what is the incidence of cancer or diabetes and everything else with unilateral and bilateral, you would find something there. And if you could consult our employers maybe see what the sick leave situation is as well, because I believe it would be lower for bilateral users. I don't have any evidence for drink and drug abuse, but it does kind of follow if you are happier with life then maybe you are less likely to go down that avenue. Those things are all difficult to measure.

Robert then introduced the idea of the financial worth of the second CI to the user- which has been looked at for CI in adults but not in terms of the second CI.

Then, finally, what is the value of bilateral implants to bilateral users? I think it should be part of research. So if I put the question to you: OK, how much money would it take for me to separate you from your little toe, a tooth or a kidney and I think if you think about that you can come to some level of money.
Then if you ask bilateral cochlear implant users whether they would permanently be separated from one ear, how much would you have to pay them? And I asked this question routinely to bilateral CI users and what do you think their answer is? In my case I say categorically I would not swap my implant, one of them, for a billion Euros or a billion dollars. It's part of me. It's not going anywhere. I can do far more with my hearing than I can do with a billion dollars and most people you ask would say it's not for sale, it's part of me, and my point here is that it's more part of us than our kidneys, our teeth or our little toes; it has got some importance. NICE in the UK say that adults only need one implant and so my question is: Why do bilateral users value our second ears so highly if we don't need them?

This led the Conversation to the challenging issue of gaining evidence for funders, to make the case for bilateral CI:

I think you have to just focus on the combination of everything. There isn't a single item that is going to convince a policy maker; it it's everything in combination. All of the benefits together, they add up, because so many of these things are so difficult to measure. Thinking about my own working life that I am in, you know, Zoom calls every day, several times a day with customers, colleagues and so on. And just because I don't need to put the effort into listening, I can actually spend time enjoying the conversation, having a laugh in the conversation, contributing without "Did I hear that right? Did I? Please could you repeat that? Sorry I am deaf", all these sorts of things going on in the background. So I am there. I am present just as you would be. And it's again really difficult to measure, but it makes a massive difference to me. It keeps me employed frankly.

I think the point around overall well-being and what you are talking about it's the totality of it all, and I think, you know, the inability to hear - obviously we all know the impacts of isolation - but it happens over time and you don't realise how much you're missing that connection and those social experiences and things like that. I actually stopped going out for lunches and dinners with friends because my neck was sore from *ping-ponging - not having to be at the end of the table and things like that. I just stopped going, and so I didn't realise how that minimising of social activities was having an impact on me. I moved less. I went outside less. I connected less. And that I think is the overall impact and the improvement that I have felt.*

What had the participants found helpful to gain benefit from the second CI? They commented on rehab, listening to on line listening tasks:

I stream a lot. I continue to do re-hab,

Also the need to be listened to to ensure the mapping (programming) of the CI system was as effective as possible was raised:

So, you know, my motivation to get CI was to hear as well as possible, and now that I have them I am determined to hear as well as the CI will let me. So I am very difficult maybe in my mapping, so I am a difficult customer to please but I have got good results otherwise, but so far as rehabilitation goes there really isn't much; just go away and get on with your life

Summary:

This Conversation was lively and on the whole this group seemed surprised how much difference the second implant had made. Common issues were:

- Improved speech perception, especially in noise,
- The ability to localise sound
- Redundancy, not being totally reliant on one CI, in case of failure or technical issues
- Reduction in listening effort, leading to improved confidence, less dependency on others, and the ability to multi-task
- Ability to travel independently
- Phone calls – again leading to greater independence
- Improved enjoyment of music
- Reduction in need for captioning
- Reduction in tinnitus reported for one

With regard to the process of second CI; varied experiences were reported, with some concerns expressed prior to the operation. Some had noticed improvement almost immediately while others had to persevere. Most had continued rehabilitation with the second ear, using streaming and on line activities; rehabilitation after CI and especially the second, has been a big thing in other Conversations on Person Centred Services.

There was a consensus that to build the funding arguments were challenging, but needed to be pursued, and it would be helpful to survey more with bilateral CI globally, and to extend the current European survey of the provision situation to a global one.
In addition, we should consider that the title of the Conversation may have led to very positive contributions, and follow up the discussion about what is needed after second CI to succeed further.
Sue Archbold, Manohar Bance, Wendy Huinck, Robert Mandara, April 2025