

CIICA CONVERSATION: What we can and can't do with our CI

10 June 2024 **Facilitators:** Qais Khan – CIICA/UK; Jehan Daboo, India; Holly Loach, UK

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Introduction:

CI users shared their experiences with CI in the ninth CIICA CONVERSATION FOR young adults with cochlear implants. Eleven young adult CI users attended, with 1 therapist, 1 parent and 1 audiologist. Attendees were from 8 countries: Armenia, India, Mexico, Morocco, Switzerland, Turkey, UK and USA.

Qais began by introducing Jehan, a certified personal trainer, a counselling psychologist and a badminton coach from India and Holly Loach, an assistant TV producer, and who lives in London. The wide ranging conversation covered some of the confusions there are about what you can and can't do with an implant, and went on to discuss how one's self image influences these in today's changing society. Jehan introduced the topic of what we can and can't do with our CI and began with the issue of sport, important to him as a badminton coach.

The impact of moisture on CI functioning

Depending on where you live or holiday, the humid weather can really affect the performance of a CI.

I don't like the monsoons, I don't like rainy season because my devices get wet, because my devices get spoilt,

India is a very humid country, so therefore I have to worry a lot more about the moisture affecting my device.

Using the dry box which is supplied helps with this problem, but the participants recognising they don't always use it well. One had only started using it a year ago, and another commented:

the thing with moisture, it can be quite challenging to maintain because I have the dry box, I don't use dry box every night because at the end of the day I get so tired. . So it is pretty difficult to maintain it every night. Yeah. And I can feel the performance going down gradually, like the sound feels a bit different. It feels like the quality is reducing in each ear

What are the issues with participating in sports?

Water !

There have been long standing problems with water and moisture and CI, and the industry has been trying to address this in different ways. Jehan began with sharing his issues, before opening up the conversation:

I went on a holiday recently to Thailand. And I was a little sceptical about wearing my aqua. Because the aqua for me can be a little uncomfortable. The sound is not very clear, in that case. So, in that situation, I went without the aqua, I wore my devices. I went without the aqua and I did kayaking. I basically got on a boat into the sea. And all the while I was like, I hope I don't fall in the water, I hope I don't fall in the water, I hope I don't fall in the water. So that stress was constantly playing on my mind throughout the whole experience, I hope I don't fall in the water, I hope I don't fall in the water

I don't like to go swimming because I cannot hear my friends when they speak, when they communicate. I would love to go sailing but I cannot because I am scared, what if I fall in the water and my device gets...

Water and Sports and CI

The problem with CI in sports has been mentioned in previous conversations and came up with several participants:

I would have to always do swimming lessons without hearing anything. Especially from your coach - I am assuming, which was pretty difficult. I too can relate to this. I took swimming lessons when I was really small, really little. After a point I did not do it because of this issue.

I've taken swimming lessons and tried using an Aqua Case but it hasn't been very effective because the sound is too low and I couldn't hear my swimming instructor!

Holidays can involve water too!

On a trip with my friend in the US and then it was like rafting trip with maybe six people, yeah. And it is kind of so nervous because you don't know what is going to happen sometimes, we jump out... we just push each other to the water and it is so scary. I took covering for my cochlear because if I didn't I would not be able to hear people, to understand what they say. I'm not able to follow the guide the kids jumping on our boat and trying to take me to the water and it was so, so scary and to think about what we can do to keep our cochlear from the water, to keep it safe. yeah, that was my experience.

Although industry has developed ways of managing the impact of water with coverings, there were many comments that they were not as helpful as they might be:

I found the aqua case quite annoying and rattled / muffled and the sound wasn't very good..

Yes I can relate to aqua kit reducing sound a lot in swimming even outside like the sound is very blurred as microphones are covered over!

... so, and the quality of the aqua case - the sound drops a lot. I think we have all experienced it

The audiologist on the call commented that she didn't know that the covering had such an impact on sound quality.

The discussion then went on about how to be able to do these things, and how to advocate for oneself, for example in water sports. One suggested:

I know it is very difficult to advocate for yourself, but before going into the situation, one could even talk to the instructor, say, hey, look, I have this thing and I think that maybe we could communicate a little differently, you know maybe speak a little slower. Maybe speak a little louder when I'm wearing this because I cannot hear very clearly. Ask the instructor to talk to you before getting on to the raft,

and be like, OK, what exactly do you need to keep in mind? Because out there I will not be able to hear very well..

Sometimes it's the groups who need to be informed; and their behaviour not only impacts on those with hearing loss, but others:

But sometimes when you go with groups, sometimes they are absent-minded. Just too hard to say to everyone, remember I have a cochlear implant because my friends are like crazy. Sometimes we do crazy things and we forget it all. Like we forget that our friend had the glasses and then they broke her glasses during rafting

For others, thinking about their CI stops them doing some sports; and they find the CI is affected by sweat:

I never use my CI while playing football because it damages my CI easily due to sweat.

Others had issues with sweat but also the device falling off:

sweat, moisture and contact sports. The device falling off. OK, sometimes you play and your device falls off or someone pushes you and your device falls off.

I worry about keeping CI in beach volleyball as the sand gets in or I lose it somewhere in sand and it gets stepped on, tried beach volleyball before with headband on to cover it securely

Sometimes when I play badminton, there have been times when the magnet has come off. And I have had to hold it and continue playing. You know!

What about travelling – and going through scanners

The discussion was lively about whether to go through the metal scanner or not. It used to be very clear not to go through the scanner, but now not so clear – and there was a division amongst the participants between those who went through the scanner and those who wouldn't.

I used to get scared that, you know, what if I get pulled aside? Then one day...., I just said, you know what, screw this! I am going to walk in through this. I walked in. And thank God nothing has happened! And ever since then, I have always walked through the metal scanner, especially at the airport . Sometimes they ask, the person who does the checking, asks what is this device? So I tell them I cannot hear so I wear it. Says, OK, cool. Move ahead.

We have been constantly told about cochlear implants, oh, you know, you are not allowed to go through this because, you know, the map, the programme will be wiped out. It will be spoilt and all of that and clearly, that is not the case.

I have been 20, 30 times through metal detectors and it was never an issue for me actually. I also was in the beginning. I say it like you, Jehan, security, so I go through it and it was never a problem for me actually.

Others remained not certain:

if at some point it was a possibility that you could go inside I would not go inside because it freaks me out.

The group was asked if they had asked their audiologist for advice – and one commented:

I always carry a signed document from NHS Hospital regarding the airport scanner so they can read and acknowledge my cochlear implants

What about switching on and off before take off landing?

Earlier advice was always to switch off the CI on take off and landing; and once more there was uncertainty about current advice.

I was told that when I was younger. That when you are taking off, you have to switch off your devices. When you are landing you have to switch off your devices, and I used to do it. Then one day, I left it on. Obviously nothing bad happened. So, there are certain things out there that you can check with your audiologist and ask for the current advice.

Contacting audiologist

Discussing how easy it was to get advice, it was suggested that people should ask their audiologist for advice and the audiologist on the call suggested that people use text – she found that helpful so that she could then call back when she was available.

Can you easily contact your audiologist by phone? In my case, yes. How easily are you able to keep in touch with your audiologist and have a conversation with them about these topics? We have a mix of cochlear implant users and professionals here. So, we are all trying to get each other's perspectives

I usually have remote check on nucleus smart app to monitor my implants performance remotely so I honestly think it saves so much time for me from going to audiologist especially when studying in university in different town

I usually have remote check on my phone to monitor my implants performance..

Wearing helmets

I recently went to go-carting and it required, to do that we need to wear helmets. And the helmet hasn't been very, you know - supportive but the cochlear implants and has squashed and also wearing glasses might be very extra difficult to wear a helmet.

Challenges at the gym

The loud music at the gym can make it challenging, although this is the same for many hearing people:

and I was listening to music through my phone's bluetooth and I did not pay attention to people and they were calling out to me, but it is a bit embarrassing because they don't know that I cannot hear them. And then as well it gets awkward in the gym. Especially when it gets crowded and people are waiting for their turns,

Advice was given to help:

What I have found that has helped me is that when you know that you are around people, reduce the volume of the music a little bit if you need to communicate with people. If you are just sitting on a bus or transport and you want to be on your own, then blast it. If you need to communicate with people, that is when I sort of soften the music a little bit, just enough to hear the music well and just about to listen to people if they are calling out to me.

Moving to discuss the challenges which are often unseen and invisible

The conversation began with the challenge of the expectations with CI and everyday reality.

I go to these audiologist appointments and they always say that I am a good user and I am getting a lot out of my implant and you know, in lots of ways it is sort of really made me kind of be quite integrated in lots of ways in society, and I can go to work. I went to mainstream school. I had a lot of hearing friends. But it is like the better I get at being part of the hearing world, the sort of more invisible that my disability and my deafness becomes.

I think one of the problems is that the discourse of the CI industry is often that once children and adults get implanted, they don't need anything, they are just like everyone else. What you are pointing out Holly is that CI users are NOT always like everyone else and that it is OK to have needs and ask for accommodations/access!

And what is important is to combat some of the stereotypes about CIs as miracle devices

Making needs clear

Yes, our needs can be overlooked and that can be in wider society and potentially also with ourselves as we kind of sort of can overlook them and we just adapt all the time. I find that at work I am always just concentrating on working really hard to keep up with everyone. And I don't always express my needs as much as I should.

I would say like, how I feel. I feel like they don't see it sometimes or they just think I am too normal so don't give me what I need. Or they do it too much, like... to talk nicely and everything, I mean, it is weird.

When the needs are not obvious, then it can be difficult to advocate for oneself:

I definitely feel quite self-conscious of technology. Like I know some people are really good at getting their mini-mic on the table. When I am around my hearing friends I find it quite daunting. It just highlights the fact that I have something and I am very used to just adapting and pretending like I am like everyone else.

when I was younger, 12 years old, I was trying to always hide my cochlear implant because I sometimes gives... and you feel uncomfortable and when I grew up, I just realised that it's not, it's not an issue.. When they ask, I just quietly try to explain to them what's that and I tried to give them more information how much I can hear , like, maybe I can change something like that, that way. Maybe not. But I try to do my best and even if I don't hear something,

In the US it was so hard for me at the beginning of the year. Because Americans speak very fast and it was so hard to get what they say. I was like, OK, just don't worry. If you need just something just ask that. It's not like shame to ask, if you miss something. I just worked on myself and now I can just freely ask people. You know, I miss something and can you just repeat it? And I try to encourage other people to repeat if they need something.

The audiologist commented:

I advocate for clients with teachers and coaches but it is harder with young adults because sometimes it is difficult to know if they want to advocate for themselves or if they want me to help with that. It is definitely a challenging thing we have to kind of empower each other and make sure we provide the right environment for people to express what they need. It can be very personal. It is

the balance, people with cochlear implants shouldn't always have to say what they need. It should be, we should, it needs to be a structural support as well

Ensuring that one is aware of one's rights and what is available

There was a discussion on the challenges about what support is available in society, whether when you are deaf and use a CI you are not recognised as having a disability:

I felt like, I am sure there are so many things that I qualify for, as a person with a disability but I don't even know about it.

*But we have to really kind of make sure that cochlear implant users are specified and included within access in services, like, for example, I found out like about a year that I moved to London that I was, I qualified for a freedom pass, which is like free transport basically around the whole of London. And I had no idea that this existed. Then when I sent, a friend of mine told me, you'll qualify because you have a cochlear implant. I was like, really? **I sent my application through (for transport access). I said I had a cochlear implant. I didn't qualify for it. It came back and they said you qualify if you are deaf but not if you are a cochlear implant user. I explained you have to be deaf to have a cochlear implant.** Eventually - it took about three months. I eventually had to find evidence that I was deaf - it was a - it took a long time. That kind of thing it makes me think that sometimes having a cochlear implant as a need and as a disability can be overlooked. **And I have had to learn how to communicate what I need and actually see myself as a deaf person as well as a cochlear implant user.***

The discussion went on to discuss how people can be really helpful:

*I think people are much more willing to repeat and help us than you might realise. And I think highlighting that we have a cochlear implant is really important. Like, when I was at school I always felt self-conscious and always wear my hair down. Now I actually want to get - I want to get a white one, just to highlight it. **When we talk about it more, it highlights we are not just hearing people or not just deaf people. We have these implants which help us.***

The discussion went on to consider how these young adults could ask for what they needed, for example at work.

so we would love for all companies to be extremely inclusive across the board. However, that is not the reality. So, and I have people who have actually worked on this and have actually challenged this and figured out how to deal with it. One way is by creating a list of ways that you feel like you need supporting, And saying that this is what I need from a company. For example you are in a meeting. You would like the minutes of the meeting sent to you, for example. You would like closed captioning on a video call, like a Zoom meeting, Not demands, but certain rights of yours that you feel apply to you and your difficulty and your disability, if that is relayed to the company, that may help.

I remember at uni I sat on the front row. I didn't like it. It is the same thing with technology sometimes, having something on the table, like a mini-mic on the table which everyone can see. It can make you feel quite exposed. But I think we have to like, I think we have to change the sort of like being, having, making it more visible what we need I think can be quite important.

The discussion reflected on the challenges of applying for a job – are you open about being deaf with a CI? There had been some difficult experiences – for example:

when I made a... application to companies, I... I did include a little bit about being a cochlear implant user. But I did not get any place in any of those. However, I applied to the next five companies, and I

removed all like cochlear implant, anything related to my deafness, on cover letter, CV, whatever and I just got interview with those companies which took me to the next round. But when I disclosed it in the interview I ended up getting rejected. So, it really is hard for me to, because they feel like I may be too expensive because they have to cater to my needs and requirements. So, it is a black and white situation. So it's a very difficult - I don't know how it will end up, especially in UK, seeing the market is very horrible right now. But it's, but it is what it is. So I am moving on. Nothing can deter me.

Another experience had been some companies which will interview every applicant with a disability, which can lead to a tick box exercise, and also the accommodations may not be provided:

other industries they always say that they will, they will always interview every single applicant that is, that has a disability. But I find that like I applied and I didn't get an interview. But they said on their thing they would always interview everyone that has a disability. But then on the flip side, I sometimes see on other job applications they say, they kind of give too much, they say they will hire someone with a disability and then when they do there's a lack of provisions for that employee in the workplace. So it is this sort of tick-boxing of diversity sometimes that can happen.

Yes although I am facing a huge challenge with my placement application as a lot of companies are still not fully catering to inclusive practices so it gets harder to apply as time passes by

What are the disability laws/quotas where you are?

Others made the suggestion to focus not on weaknesses, but on strengths. For example:

Yeah I already applied to many different companies and agencies. I am working as a... designer. What it has taught me so far in my life is we shouldn't focus so much on weakness which is on our hearing and lack of it. We should focus on our strengths as designer I say, I don't know... I see better than you guys. I see more clearly. And this is my strength. I focus on my strengths and it helps actually to shift instead of to my weakness. But it is has worked so far for me actually. I don't know how your experiences have been so far.

we have to utilise having cochlear implants and say it is something that gives us tools that are really useful in the workplace and I definitely find I say that having cochlear implants actually makes me a good listener because I am fussy what I hear. I have said to employers I am a hyper aware listener. I can not take hearing for granted. What I do hear I catalyse on. because I do think it has given us a lot of strengths having cochlear implants. I think there is a lot we can gain from it.

in making one's needs known you have to keep reminding people:

They apologised that they forgot about my condition. Even though I have a nice and understanding team they sometimes forget... yeah, absolutely. It is important to remind them. Yeah, absolutely. I have had experiences like that.

Comments and changes in societal attitudes:

The participants felt that this was a real community of young CI users from across the world, where there was a strength in discussing these issues:

Yeah, yeah, this is a real community here at CIICA. Being from all around the world, I think it really makes us realise that it's - there's a real universality to our experiences. It doesn't matter where you are in the world - it's... there's always, there's a whole community of cochlear implant users and society is actually becoming more accepting of difference and diversity, eg, neurological issues and

hopefully recognition of diversity and deafness will grow as the numbers grow. I think we are beginning to move away from binary definitions as a society which is really important. I think cochlear implants are part of that.

AND/BUT there's also a tension here because on one hand, more accepting, and on the other, there's also more of a focus on fixing/curing/rehabilitating— ie, think about Elon Musk's brain implant pronouncements, etc. So we have both. More acceptance AND more of a desire to fix

It's a huge issue society isn't addressing and doesn't know what to do about..

The Conversation stimulated a challenging discussion raising many issues, some of which have been considered before, but this took them further.

CI are a technology which has brought major opportunities but also challenges – some of which are yet to be worked through.

Sue Archbold, June 2024