

CIICA CONVERSATION: What would you like to design and change of our processors/accessories?

16 September 2024 Facilitators: Qais Khan – CIICA/UK; Gargi Agrawalla, UK

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Introduction:

CI users shared their experiences with CI in the eleventh CIICA CONVERSATION FOR young adults with cochlear implants. Nine CI users attended from 7 countries: Belgium, Canada, Finland, Morocco, Spain, UK and USA.

Qais began by introducing Gargi, who is studying product design and technology, and had designed EarBoost+ as part of her university course and won an award for doing so. Gargi explained what had inspired her and what she had designed:

Designing the Ear Boost+

One of the most exciting aspects of my studies is the chance to work on projects that don't just focus on technological advancements, but also consider the product impact on people's lives and the environment.

The idea for the Ear Boost was my experience with hearing friends and we have been out camping for a week and I quickly realised how difficult it was to look after my cochlear implants without access to electricity and I brought along a traditional dry box but it required power to function properly. So unfortunately my nearest power source was too far from my tent and I was forced to rely on disposal batteries which didn't last long over the course of the trip, and I ended up using about four batteries which is not only created waste but also made me feel disconnected and dependent on technology.

I wanted to get a solution that would allow people like me to maintain and care for the cochlear implants, no matter where they are without worrying about access to accessories or the environment, harming the environment. So my product is a portable wearable device that not only was a device for drying the processor which is so important for humid environments because what happens is that sound quality degrades over time if you don't look after it properly, and you need to dry them regularly. It also charges them at the same time using renewable energy sources like solar power technology and piezoelectricity. This means you can confidently go to remote areas knowing that they have sustainable ways to care for your implants.

And my goal with the EarBoost is that it empowers cochlear implant people like us with greater independence, freedom and sustainability, whether travelling to really far places, whether you are going to Ireland or Maldives for example or climbing Mount Everest if you really like adventures. So you don't want your implants to limit you and you want to look after it properly at the same time.

So for me, like, right now we want to use technology like iPhone but we want the same for accessories with cochlear implants. So we want a smaller compact size which is very modern, sleek looking and it functions two ways - dry and charging at the same time.

Gargi had won an award for a plastic sustainable initiative and now was seeing how it could be developed. There followed a discussion about the different CI companies and if it is possible for one dry box to be used with different models and batteries. There were comments that the dry box hasn't changed in recent years:

Yes, the dry box is very old and they haven't changed; they haven't really innovated it much over the years.

There was agreement that the current dry boxes are big and make travel difficult:

I can dry both but the problem is that the dry box is too big. I have a ruck sack and when I go around the world and I travel with my ruck sack, the dry boxes are almost too much space and it's so -- my ruck sack has too much weight. So for me it's very difficult to travel, because of the weight on my back.

I travel all the time, and I always have a carry on, I never bring my luggage. I put my cochlear implant stuff in the back pack and it's always a pain, a pain because of how much stuff you have to put in there

I remember being in Costa Rica and the room that I was in only had like one outlet to charge the battery and from, like, to charge anything, your phone and it only had one and I remember, so shall I use the dry box or charge the battery or charge my phone?

Some dry boxes were for only one CI, and you needed to have two:

I have a friend that has - she's from Austria, but she's got like a dry box but it's smaller than this one and I think it can only carry one, like, one CI because it's very small.

There was a great deal of interest in talking about totally implantable devices, TICI, and CI processors which were truly waterproof and windproof.

Leo pointed out that it appears that people often don't use their dry boxes:

I am collecting spare materials of CI for Ukraine, spare materials, things that people who have a cochlear implant don't use. I must say in the last year in Belgium I have received more than 50 dry boxes because everybody receives dry boxes who receives a cochlear implant, and they don't use it. It's, as you say, it's too big, and so it's often wasted money what the companies do, and they give dry boxes but I think more than half of them are not used.

The challenges of daily charging were shared:

my outlets here are limited, like, I only have two and I need one for my laptop and I need one for my phone and for my deaf alarm and my dry box, so I don't use them every night because I don't always charge. I do not have the time to charge it; because I have to charge other things.

However, the comment was made that you SHOULD use the dry box and you SHOULD charge daily.

You have to do it daily like for example brushing your teeth or, you know, it's sort of like you charge your phone: I sort of have got used to it.

The discussion continued about how sweat can cause problems needing the dry box:

And so sweat really damages the processors, but it happens so fast I can go from having a dry perfectly dry processor to having a broken one in less than 30 minutes, just due to sweat. And then at that point if I put the processor in the dry box, it invariably dries out and works again, so it's useful to have the dry box for those situations. But most of the time it's just sitting there, sort of being unused and a waste of money.

Cochlear implant and Hearing Aid?

The discussion continued to the provision of a hearing aid in one ear and CI in the other, and the challenges that brings.

I have two cochlear implants now, but I had an implant and a hearing aid for 20 some years, and yeah, and that was very annoying. I mean, I am in the United States so the medical technology is a little bit different here I would say. But I was able to Bluetooth my hearing aid to my phone but not my implant, and a big part of the reason I upgraded to bilateral implants was because I wanted them both to Bluetooth to my phone seamlessly and it works.

My case is that I have a cochlear implant and I have a hearing aid in the other ear, and my audiologist says that I cannot get Bluetooth yet because there is no Bluetooth setting that could work for both the cochlear implant and the hearing aid. So I was wondering if any of the people here have a cochlear implant and a hearing aid? And if they do have Bluetooth because I don't get, I don't have it and I struggle without it. I can't make phone calls or anything.

One participant advised talking to your audiologist – but being clear about what you want:

It's just the case of researching companies and going to the audiologist and you have to say what you want. I know it can be hard, but you have to say how it's affecting you; you have to like stand your ground and then they will take your case and hear from your point of view.

Leo explained how AB works with Phonak hearing aids, and Cochlear works with GN Resound hearing aids to overcome the problem of HA and CI working together, and being able to use Bluetooth.

The practicalities of wearing CI

It's just I thought about the processors, like, for me like I am very small, sometimes I feel it's too big for me; it doesn't stay on -- it's because it's too big on my ear and I wear glasses sometimes and I am like, Oh, all I want is for a processor to be smaller so I can put on my glasses

Another participant commented about the issue with glasses and CI:

My last glasses had straight arms – they looked good but sat on my implants. So, while everyone else is thinking about frames round the eyes, I'm concentrating on the shape of the arm.

So it could be advice to choose carefully which type of glasses fits the best for you.

Sports including swimming.

Taking part in sports always comes up in these conversations: and the challenges of keeping the processor on.

I cannot have a strong magnet but I work out a lot, and it's because I always have to wear like a band or something on the head to make sure the cochlear implant doesn't fall. But it gets tight and it hurts; it's hurting sometimes after. So for me I would love to have a processor that is smaller

With swimming there are many issues:

Then the alternative is you wearing the aqua kit but if you are anything like me, then you don't get on with the aqua kit because it makes all sorts of funny noises that you can't really understand. It sounds like hair is pushing on the silicone even though it isn't. So it's not an ideal solution.

The aqua kit is for me not a good kit as it gets the sound very muffled.

The conversation moved on to thinking about helmets for sport and the issue of getting helmets which fit, and some design ideas:

So it's definitely the helmet protection, there has to be some kind of a kind of design so I have ideas for some different designs with the helmet which basically looks like, you know, the seashell, the conch seashell. So it's sort of like the design I am working on

I think actually I think I have seen one of the projects that has been done in the US where they designed helmets for American football over the cochlear implants. I am not sure if anyone has seen it?

I play softball and I can't wear my CI with my helmet.

The chat room was busy during the conversation, confirming the comments in the conversation and the lively communication between the group.

Summary

The key points were:

- Great interest in a dry box and charging box, and feeling that the design should have moved on
- The impact of humidity and sweat and water (rain, Swimming) are underestimated
- Practical issues of travel with CI (this regularly comes up)
- Battery life
- Practical issues of daily wearing : glasses, helmets for sports, falling off
- Bluetooth capability
- Balancing HA and CI

Living with the changing technology made the group aware of issues and concerns about reliability and the future of technology:

I am 20 years old and I have one cochlear implant because I had my other cochlear implant removed this year because it failed. Now I have one cochlear implant I feel like I have more problems with hearing and I do worry about the future.

This group had lots of creative ideas to share to improve their management of the technology and we look forward to further discussions.