

## CIICA CONVERSATION: ON line CI services: What's working, What's missing, and What's next?

**2 June 2025** Facilitators: Qais Khan – CIICA/UK; Jess Hissam, USA

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### Introduction:

CI users shared their experiences with CI and on line and remote services in the thirteenth CIICA CONVERSATION FOR young adults with cochlear implants. There were 26 attendees, with 15 CI users from 11 countries: Armenia, Austria, Belgium, Canada, France, Germany, Spain, Switzerland, Turkey, UK, USA. Attendees also included audiologists, psychologist, teacher of the deaf, ENT and industry.

Jess began by introducing the topic with her questions, before opening it up to the floor.

- What has your experience been like with online and remote cochlear implant care?
- What type of support do you currently receive?
- What barriers or limitations have you faced?
- What's working well for you right now?

### Experience of online and remote CI services

Within the group there was comparatively little experience of remote care or online services. Qais asked for a show of hands and less than half the group had experience, and those who did, it was generally related to checking functioning or using the app: .

*I can see that not many of us have used, you know, CI online service*

*Well, I don't have much experience with Remote Care, just because I have the privilege of being close to the cochlear implant clinic.*

*In the UK I have not had much experience of Remote Care. I just received my, the only extent to it really is that I received my new cochlear implant processor and that was delivered to me and then I set it up kind of online and then they said they were going to follow up with an appointment to check in. So, but so I don't have a load of experience.*

*I don't have any experience on Remote Care but I feel this was so interesting because I didn't even contemplate the option like. I don't even think it exists here where I live.... I definitely will have to search and investigate on it.*

*hi we don't have online services here in Turkey. But it would be useful in terms of time perspective because we don't have enough time to test our new mappings in real life. For me, at least, it feels I got mapping half an hour at the maximum for my mapping and I just go home the same day and I don't have the time to test it. But you know, living in the map*

*would be beautiful. It would mean a lot to me, from the time perspective but it is still sort of anxiety for me as well because the audiologist may not always be open to working flexibly with the CI users, especially online because it is still hard for me especially in the first month to understand digital means of communication.*

*I agree with everyone's points here and I think it is really important to stress that it is dependent on preference. I am very used to seeing my audiologist in person and would find an online experience more bizarre than someone else who would perhaps prefer that experience instead*

*We should find a way to balance things out for the audiologists for us, to teach audiologists how to be patient, how to stay flexible, how to ask the CI users what their preferred mode of communication is. Do they prefer video calls, texting, you know, just sharing it by e-mails. I don't know, because I didn't have any experience of... before. I am hopeful for the future. I.*

### **Relationship with the audiologist**

There were several comments that the relationship with the audiologist is valued, and needs to be maintained somehow, even if it is online.

*Personally I have been used to seeing my audiologist once a year, even if everything is fine because the overall purpose of seeing the audiologist is to have a conversation with your audiologist,*

Some expressed concern that they would lose the relationship they have which was considered important:

*When I was first told by the audiologist it was moving online, my first reaction was like, anxiety and fear that it was kind of like a bit of a, you know, sort of charting away and we weren't going to get that one-to-one intimate care. And I think that growing up, my experience, my like relationship with my audiologist was really important and I had the same audiologist for like my whole life until I was about 16. So, I think that in-person care is important. From a sort of point of view of, I guess holistically is maybe the right word, and feeling like you can vocalise what problems you might have and sort of, I don't know, it's, I had anxiety originally about Remote Care. Maybe it will be more efficient. But I also think there is some things about in-person care which cannot be replaced*

*I think it is important to acknowledge we have healthy relationships with audiologists which is wonderful*

### **Challenges**

Good access to Wi-Fi and the use of complex tools and systems can be big issues. One participant was running research programme looking at the use of remote and online systems in their clinic, and working with all three manufacturers. All manufacturers are working on these developments and for those clinics working with all of them this can be a real challenge, needing different tools and systems:

*because we are working the three manufacturers and they are so different with the tools we can access... is that we are providing aftercare during*

*We are running a study because we want to evaluate what is the value for our patients and for ourselves? We have combined remote services, which means remote fitting during the first year, we have combined it with speech therapy because it goes together for us.*

Jess asked for clarification about when remote fitting would begin as it was felt that it was not appropriate at first.

*We do the first activation in the clinic. We do see the patients at their first month's follow up. Three months follow-up. Then we ask them at the three-month follow up we ask would you be interested at meeting me at the six month appointment online? .....I really appreciate some of you said the need, the relationship to the audiologist, absolutely. we implanting over all ages and yes, sometimes the 60-plus population sometimes they are not fine... It is easier for the younger generation, of course.*

*For some of the patients, they just love it. For some of them it is just too much because we show the app. We install the app. We give all the handouts. Really everything to the parents, and still once we have to the appointment it is difficult. So it really depends on the needs of each individual. I understand some clinicians who say it is quite an effort to set it up.*

Another challenge that was mentioned is that not all available facilities are available remotely:

*Maybe my wish to have that access to all the fittings when we do remote. We do not have access to all the little things we want.*

Taking photos for a remote check...

*so I was at uni in accommodation and I had this Remote Care appointment remotely, on my phone and at that time I was in an awkward situation when I had to ask my friend do take a photo of my implant area so it was very like, because I can't do it myself.*

*What information do you get from the pictures we took on our magnet areas on the head? Even if it is over ten years of surgery, so - I am not sure what, why did you need the picture?*

*Basically remote check is designed to reflect what would be commonly done in clinic. So, what an audiologist would do in clinic would be to look at your implant site to see any redness, soreness, whether the magnet is too strong. What we are looking for is any irritation or soreness around the implant site.*

## **Advantages**

Online services were seen as offering more flexibility and better use of clinic time:

*From a time perspective, I think remote care is kind of perfect. In the clinic, we usually have limited time during appointments, and we don't always get the chance to really test how the new mapping works in our daily life right away. With remote care, we could actually live with the new map for a bit, see how it feels in real situations, and then easily schedule a quick remote session to fine-tune it if needed, without waiting weeks or months for another in-person visit.*

Remote services can identify issues which need to be seen in the clinic:

*the remote tech for the app of the manufacturer that I am with. And it does help in terms of having me do a series of questionnaires and sound tests, and then my audiologist can take a look at it and see if there is any potential red flag and have me go in for a full check up.*

On line services could save the drive for families:

*It was like a drive when I was a kid. It was a drive for my parents to get me to the appointments, and it would have made things very easy, because every time I had a little problem, especially when you are younger (we had to travel).*

If you travel to a different country and have a problem, it could be useful to contact your familiar audiologist, to help solve the problem: one experience:

*I moved countries a couple of years ago. Now I am planning to do it again. And after being there for six months I had a problem with my programming, . But it was very frustrating because I went to the audiologist in Australia, they couldn't solve the problem. And it felt a bit like you are flying out of the nest and nobody knows. It is like nobody knows how you are hearing and they were like, well the map is very complicated already, so we don't want to touch it more in case it actually gets worse. It was like, yeah, but I am not hearing well.*

*So when I moved to France from the US, 15 years ago, having French not my first language I waited a very long time to make an appointment..... Because any time I would go to the website of the clinic, the only option to make an appointment was to call on the phone. And I'm like, it is not even my first language. Dates and times are like the worst thing that you could be faced with. So it was really interesting and a little disappointing to be honest, France has a wonderful service where you can book any sort of doctor's appointment online but not for hearing.*

*I can see this being practical when we are traveling abroad to be able to access help remotely. Before, I felt I had to find a way to get a back-up processor in case the primary one fails*

For young people travelling they could see the real advantages of remote services, but also for the older person with CI, it could be seen to be helpful:

*A 92-year-old lady in the US, that is in a memory care unit. Now, she's still is doing quite well but here is an example, as we talk about cochlear implants for the lifetime, here is an example of someone who is not able to go to her clinic. She can't leave the facility and her processor is not working. So that would be I think another example of where Remote Care, even just to get her back with functioning, figure out is it the cable coil or something simple?*

Suggestions were made for the extension of online care to support more customised mapping or programming:

*I really like what your comment because Remote Care can make a huge difference especially when adapting the implant for everyday environments. As we grow up and move through different settings depending how you like to hear, you can really customize your hearing but sometimes we need some time to do some trial and error. Rather than thinking about online care as being a full remap session every time. If we could have a quick tweak of something to see if it works for us or not, I think that could be hugely beneficial to our care.*

*One thing with that, even that I have just noticed, when I look at research protocols there is a big push for streamline mapping which is not inherently bad but it is not the right option for all people. I think there needs to be more research that shows and demonstrates that we do need customised care.*

Online mapping could support the online care and help industry see what is really going on:

*I do think there is a possibility that online care and having that access would help manufacturers see the variety across the spectrum for the mapping we need as well. Not just a one size fits all. It creates the opportunity for collaborative care for audiologists. They can discuss cases with doctors, consultants more freely. And research into pushing it to the next level having that flexible system would be a game changer,*

*What we need to do if somebody doesn't have access to Wi-Fi? Could we do online care through the cellular data? Is there a hub where that patient could go to that is private in their home town where they can have Wi-Fi so they don't have to travel distance to see their audiologist, for example.*

#### **For the future:**

It was felt that training is needed by both audiologists and users:

*Would it have been nice if before we do Remote Care for everyone, should not everyone have some training from audiology on how to use Remote Care, on their mobile phone equipment, before in the future they can comfortably use the Remote Care app? I thought that would be really helpful because initially I never had that training. So I had to explore it myself and it can be like, at that time, so think about elderly people, how would they do that. They can't do it. I would say training for everyone would be really helpful in the future.*

*For the future, I would really like if everyone gets trained by an audiologist on how to use remote care even if it's for 15 minutes - it goes a long way for all age groups*

CI services were recognised as being very short of time – and remote and online fittings were seen as both helping this, and being a problem:

*Cochlear implant services may not feel ready to offer Remote Care because they are too stretched for time. Other people are saying Remote Care is the way to go if you are stretched for time. So there is kind of a tension here about whether Remote Care can support cochlear implant services dealing with the growing range of patients? Or does it put more demands on them?*

Use of AI: While the group were enthusiastic about the use of AI and the opportunities offered, they were all realistic about the issues it raises:

*We have some good questions about the use of AI, which I love. It is a reality where we need to consider the safety of patient's data and their protection as well. Especially in this day and age*

*And also we have to consider what's the likelihood of someone being able to "hack" into our CI processors through the app and mess things up, not that I can see the value of hackers doing this - but something to think about as we witness the evolution of health care in general.*

*I think in today's time, there's still level of concerns on exposing patient's data and privacy with use of AI - I am pretty sure it's a big topic of discussion in healthcare systems today*

*Machine Learning is the properly the technical word to use, there's a lot of information about it if you google it! I'm sure it can be implemented into cochlear implants!*

Comments were made that there could be an apparent discrepancy between what the manufacturers offer and what the clinics offer:

*I think it is helpful for the patient to be educated about what the options are, about those offered by manufacturers.*

*There is certainly different perspectives as we look at this in the realm of Remote Care. There is a lot of potential to go with Remote Care and it is the future. What I really just want to highlight is looking at the use of the role that we play in the landscape, as the patient, we have a responsibility to ourselves to be informed of the different technologies and the services featured that are available. And we can get that through the manufacturers that we are with and then I believe it is the manufacturer's role to educate the recipients on, these are all of the features which are available. And then it will be up to us to share, to bring this information and say, this is what we have learnt and ask the clinician if they are able to offer that at that moment because we know that different clinicians have different capacity*

There was a discussion about how useful it would be to evaluate the programming in the workplace, where the user spends most of the time:

*Agreed with D, it'd be nice to have remote mapping done in the actual workplace. For example, someone who works in construction can be in the worksite and have the processor mapped, then report immediately on whether the sound they are hearing is suitable for them as the adjustments are made.*

Comments were made about the age of take up of remote services:

*I do wonder if there's data to show what's the uptake on remote care based on the age demographics.*

*At what point can children with CIs start learning how to use remote care features?*

Flexibility was considered important:

*What we are trying to achieve is flexible care so there are choices for the patient in how they are supported. It is up to the clinics how they use these technologies. Most clinics offer a hybrid approach with a mix of face-to-face and remote visits.*

An older long term CI user commented:

*I always like to listen in on these conversations with the young people because there is so much interesting information which comes from them as well. You know. Just really great. Really great information. And things that can be even used with the older people that I am working. So, thank you all very much for allowing me to join you.*

### **Summary :**

This conversation was very popular and lively with requests for follow up. The following issues emerged:

- The group was very interested in the topic of remote and on line care, and wished to know more.
- There wasn't wide experience in the group of remote services
- They valued the relationship they had with their audiologist and didn't wish to lose that.
- They considered training was needed by audiologists for people to use on line services with confidence.
- They felt on line services gave more opportunities for more personalised and flexible care.

- They wanted to be able to go home, to school or to work to test programmes out where they were to be used and get remote services there.
- They recognised that while training and familiarisation with the technology may be time consuming for clinics, in the long run it could save clinical time, and enable them to see more people.