

CIICA CONVERSATION: CI Remote Care: Designing the Future Together

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Introduction:

CI users shared their experiences with CI and on line and remote services in the fourteenth CIICA CONVERSATION FOR young adults with cochlear implants. There were 10 attendees, from Belgium, Canada, Chile, Germany, Switzerland, UK, USA.

Jess began by introducing the topic by commenting that in the previous conversation

One of the biggest things that we heard in the last conversation about a lot of young adults which they had in terms of Remote Care or access to online CI care was the fact that after they get adjusted they wish they could have online version where they could check in with their audiologist. If we transition to online care, how do we keep connections and relationships with audiologists?

She went on with her questions, before opening it up to the floor.

- **What's one digital feature or tool that could make your CI care easier?**
- **What are small ways online care could add to your connection with your audiologist?**
- **If we had funding for a global innovation challenge, what solution you would like to see?**

Ease of use was important

So firstly, thinking about the feature to make it easier. This brought many comments about the number of clicks needed to utilise some features, which can interfere with conversation with others, as they have to wait while you set the feature up.

you have to do how many clicks to click and activate your Bluetooth if you go out...

for example, when I was at work and I may have to use it, and then it would have, it takes time to set up, and it takes time to pause the moment, so they will have to wait for me to set up

Problems when travelling to another country for CI : challenges for follow up care

One therapist commented that younger students often cannot talk about their needs or answer this question. Some of her older international students have appointments in different countries which are difficult to coordinate and expensive.

For those in Low and Middle Income Countries (LMIC) who have had a CI elsewhere or for whom there is no local service, the option for online services is an important discussion. To make online services sustainable with users and families involved was important:

and there's just so many other things that are not existent in Africa and in India for support that we just take for granted in the US and in the EU. So, we really need to bridge that gap and that's what is

just so exciting right now and if we could just have cochlear implant users and parents to participate, to shape it, to what you need, is what is very, very important.

One therapist commented:

I have a client that's in France. But they have cousins that are in Senegal. They recently were implanted in Morocco. In Morocco they had their first mapping and then shipped back to Senegal and there has been nothing since they have only had their first mapping.

They are implanting these devices, saying, look what we did and then nothing!

A CI user commented:

one of my family who lives in Pakistan, and they have two kids with cochlear implants. and they live in the city but are very well not known and they had to travel to Lahore to, that is the nearest, the cochlear implant clinic and every time they need something, every time they need batteries or every time they need a mapping they have to travel to Lahore to just visit the clinic..

Another issue was raised about the quality of the mapping which was why people were travelling when they could:

But they don't find the quality of the mapping is good enough. That is why they end up going to Dubai. And they don't necessarily have all the equipment they need.

One user commented on the length of time to get an appointment and that this needed to be online.

Another therapist commented that if the fitting by the audiologist was good then the functioning of the CI was improved, and agreed with the user who commented about the challenges of listening fatigue and mental health issues. She commented on using internet service for mutual support:

I think this is just the most exciting time for cochlear implant users, the parents and the families, because there's so much that can be done..... This Whatsapp group we just started in India, through this one individual. Hundreds of them on this group, just wanting to develop something from their own needs. The needs to be developed by cochlear implant users and parents and families so that they have something that is practical to support each other.

An attendee who provides services on line for families commented :

this is just online communicating, and the problem is I think that the producers of devices on the software they should get to another approach because I think it is not the device, it is the question of how to use it. What we are doing is live online. Because live online is the most social software. access to live online technologies has improved very much.

There were comments that COVID had enhanced the use of online services and improved confidence with online services. One attendee works with services in Low and Middle Income Countries and described how they could do this.

This is in the area of remote fitting. So for me this is a very interesting core remote service. And it was a situation where urgent, or urgent help was needed, in Kyrgyzstan, where we have many projects. I asked an expert from Kiev, we have been working many times, and we started remote fitting. But what we did was then to split the technical lines, so we had logged into two instances. One, to support the fitting software process. And the other one, to support the video feedback from the child. And we did this several times.

Two instances of Zoom, which was on the same computer for the experts, the remote expert, but different devices locally. And then there also could be a third instance which could serve for live teaching and live explaining what is going on. So this complexity is, I think, good. Now I must admit it was important to talk about the concrete problems you face.

Practical challenges eg shipping laptops

Two attendees talked about the issue of shipping laptops for use in both the USA and Low and Middle Income Countries; in the UK there had been experience of this during COVID. Old laptops could be used, in LMIC and they are often available:

To ship laptops to countries and areas where they are not available, we do not use Windows operating system, but we use Chrome Book... for supporting old laptops. So, it is not difficult to collect old laptops because many people give it for free. They are happy if you care... and then if you install this Chrome... it is working perfectly and old laptops are also available in most underserved countries.

Another participant added:

I shared one of the things that our nonprofit does is we ship out a laptop to patient houses to do co-pilot programming and the thing we are trying to figure out is how to build the protocol around brand new patients when they don't have the... we have done some experiment with some patients,

During COVID many CI centres had experience of making this work. The comment was also that most people now have mobile phones, and their use is increasing with AI.

Defining Remote Care

It was felt that the definition of remote care was very broad and could include talking remotely to a specialist, or a remote check, or programming online. It was felt that for it to be covered financially, to have a definition would be helpful:

When advocating for the need for online care, what does it look like? I think it is interesting that we saw a huge spike in telehealth especially during COVID time. In the United States there are now pulling back covering for it... which will impact Remote Care. I am excited to see especially what your countries and the rest of the world are doing because it allows me to advocate for what needs to be done in the United States. we are very behind in a lot of things.

Talking about financial reimbursement for services raised the issue again of what we call things-

A gentleman in Germany: because of the name of our new support group, saying that it is a wellness group. And he remarked because we have the name "wellness" in it the German authorities would not be able to reimburse him. If he's involved in any programme, online programme, that is not in some way having a medical term. So he's brought up this entire new area of online support, which is also an issue in Canada and the US, so cochlear implant users want to have some support online. They don't, they can't get reimbursed for it medically.

Working together

There was a recognition of the time and logistical issues that are involved in making online services work and address the needs:

The reality is innovation will not happen unless we all work together, a couple of comments from audiologists on the last call, one of their frustrations is that Remote Care is a great option but where is the time to implement the whole process and what about reliability of equipment?

Jess went on to bring up another of her questions:

If we were to say, what is the one thing that needs to be like the highest priority in terms of global funding for innovation to actually bring online care, what do you think that one piece of the puzzle that we need the most?

A therapist pointed out that in many countries the technology in use was not the latest technology and would not include the latest features :

just because we are in a different part of the world, are they getting the leftovers?

This can be a major problem in getting out on line services in parts of the world where it could be even more useful, but the technology has major challenges. There are examples, of technology that has been replaced by an upgrade being sent to LMIC but not being able to be programmed in a different country to registration.

Further examples were given of the major challenges of spare parts in LMIC and in getting them there. With the global experience on the call, there followed the request for international collaboration:

There needs to be an international collaboration. It is one of the first steps with the global innovation is that everybody has to get on the same page about the processor to make it accessible for all.

I think there was a conversation we touched on as young adults and we talked about which there was a map sometimes, accessible map of where cochlear implant centres are.

The conversation concluded with the need to sell innovation and changes in practice to make telehealth available, while keeping personal services.

Summary of issues raised:

- Clearer definitions of remote care/telehealth would be helpful
- There was an enthusiasm as to what could be offered with on line services, for audiology, for therapy and for peer group support
- However, the value of face to face appointments was recognised
- There were concerns about the issues faced in LMIC for services, and also considered that on line services had a lot to offer there where professionals were lacking
- This was particularly true where people had travelled elsewhere for CI and follow up was lacking.

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