CIICA Conversation: Adults with CI talking about the Living Guidelines Project

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Facilitators: Leo De Raeve, Belgium, Lise Hamlin, US, Darja Pajk, Slovenia

Observers: Brian Lamb, Sue Archbold, CIICA

Participants: 13 users of CI; 3 family members, 1 HA user, 2 Audiologists/Researchers, 2 Advocacy leaders. Several participants have global leading roles in advocacy for hearing care.
Live captioning was provided, with text on tap available in Spanish. CIICA Conversations last for one hour and are not recorded.
Participants were from Australia, Argentina, Belgium, Canada, Finland, Germany, India, Ireland, Mexico, Slovenia, S Africa, Spain, UK, USA.

Introductions:

Leo De Raeve is acting Chair of CIICA, Director of ONICI, Co-Chair of the Living Guidelines project, Scientific Advisor to EURO-CIU.
Lise is the Director of Public Policy at the Hearing Loss Association of America (HLAA), which has a national office near Washington DC and chapters all over the US. She is a CI user, a member of the Communication Group of CIICA, and a member of the Task Force of Living Guidelines.
Darja Pajk is a member of the Steering Group of CIICA, Board Member and Treasurer of the European Federation of Hard of Hearing, EFHOH, and member of the Task Force of Living Guidelines. She is a bilateral implant user, living in Slovenia.

Attendees also introduced themselves via the chat room.

Framing the Conversation

Prior to the Conversation, participants received information about the Living Guidelines project, which is aimed at addressing the significant under provision of CI for Adults and improving outcomes for adults with hearing loss. The evidence-based guidelines will help ensure that those who need CIs have a consistent pathway for access to the right treatment. The project goal is to create global living practice guidelines to optimise the standard of care for eligible adults. They can be adapted and adopted for each country and updated continuously as new evidence becomes available.

HT Analytics, the Australian group employed to manage the project, published the Guideline protocol on Prospero, which is an international register of systematic reviews and the review is underway. The project is not a CIICA project, but CIICA is involved in ensuring that user views are represented.

This Conversation gave the opportunity to discuss the research questions which are being asked in the literature review and to put the perspective of users and families forward about priorities.

Leo De Raeve began by introducing the project, which will cover the cochlear implant journey, and these questions had been sent to participants beforehand:

1. How will the guidelines be useful to you?
2. Is something missing in the Living Guidelines?
3. How would you use them? Who with?
4. What do you need to use them?
5. How can CI-users be involved?

Summary of the verbatim live discussion, chat room comments, and those sent by email:

1. **How will the Guidelines be useful to you**?

There was a consensus of opinion that the Guidelines offer an exciting opportunity to address the **lack of awareness of CI** not only in society but among professionals, including audiologists. Several examples were given where those with hearing loss had to advocate for access to CI, and were not supported in doing so by their audiologist:

> *What we hear is there is a huge difference in how different audiologists approach cochlear implants, right from the get go, right from my own audiologist, when I was considering a CI was very dismissive.*
>
> *In my own experience, when I was considering cochlear implantation, I was seeing an audiologist who had no interest in cochlear implants: she only wanted to sell hearing aids. She gave me the impression she did not believe I would benefit from a CI. She only grudgingly provided the needed audiological evaluation prior to going to the CI surgery center. If I had relied on her advice, I would not have gone forward with getting the CI.*
>
> *On the other hand, I turned subsequently to an audiologist who has a consciously patient-centered and holistic approach to hearing loss, someone who dispensed my hearing aids, but who had an understanding of the impact of the cochlear implant and support for her patients who explored that possibility, even if it meant they no longer came to her for hearing aids. The trouble is finding these kinds of professionals is hit or miss, luck of the draw. If you cannot easily find such professionals at the very least standards and guidance should be in place.*
>
> *There is a huge need for awareness, in India especially there is no awareness that adults could have a cochlear implant and there would be benefit.*

There was general agreement that this was not only true for India but generally:

> *I think it is for most of the countries in the world, the big issue is awareness.* ***A (Lack of) awareness of the possibilities of cochlear implants today****. And also one of the main issues is also, and that is what I picked up also from L's comments, is how can we make local audiologists, local ENT doctors aware of the possibilities of cochlear implantation?*

The Guidelines could be something concrete to use as educational and support to advocacy work:

> *Considering the different interpretations, it is necessary to unify the opinions regarding when someone benefits from CI, in what kind of hearing loss. That individuals can also know when reading the guidelines when something is meaningful and necessary. Above all, it is also a "weapon" for decision-makers when it is necessary for an individual to get/give/pay CI.*
>
> *I see living guidelines in that way, as education part and something that can support organizations of hard of hearing people, about* ***when they're fighting for better conditions for people with hearing loss.*** *So, now that is something very practical - you can show that to the politicians or in the health system, yes, that is the system and what are the benefits. That is real, that is not just something somewhere in the clouds and that is very important that we can show the benefits of cochlear implants and in some way also the impact on our lives.*

If there is little awareness amongst audiologists and ENT professionals, then it was considered that those with hearing loss will not be aware of the potential of a CI for them: the guidelines could provide this information -and should be available to and accessible to those with hearing loss to use:

> *Need to provide ways of informing people they have a problem. The signs are well documented but they need to be promoted. Where to place that information.*

There was also consensus that **practices for CI for adults are hugely varied, and agreed guidelines would provide opportunities to increase access and rehabilitation**. Hearing screening was mentioned as being important to address so that discussion of hearing loss becomes mainstream and provides the opportunity for timely fitting of hearing aids and implants. The WHO Screening Handbook already has evidence-based recommendations for the implementation of screening.

> *By taking these first steps for screening and referral standards, the promise is of a greater number of adults with hearing loss learning about and benefiting from CIs.*
>
> *What is not clear for me is who the guidelines are meant to be used by, whether the end user has a potential to be the user of the guidelines because what we have said so far is that OK, the doctors may not realise that you are a candidate, as L said,* ***but how can the users self-identify and self-refer as candidate?*** *Because I can say myself, I never felt that I was quite*

> *deaf enough for CI. And it took me 20 years to come around to the fact that I was. So, if I had been able to say at the start, OK, my hearing is at this level, I should qualify for a CI, then I then have grounds to argue with the clinic or go to another clinic, but as it is, I think most candidates do not realise that they would be candidates because no-one is telling them, they have no way of knowing.*

This led to a discussion about the ability of people to self-refer for CI and some mixed information; self-referral does not seem routine, and it was seen as desirable.

> *Right now, we have situations where patients are not fully informed about going ahead with implantation, especially controversial ones……. So, how can these guidelines potentially make that change from just a clinical decision to also getting the actual person involved (in the decision)?*

There was a recognition that audiologists may feel they "lose" their patient if they refer for CI:

> *I think one of the reasons why audiologists approach in different ways is because we don't often have the follow-up of the patients once they have been referred for cochlear implant. And I have met someone who said, when I refer someone, I don't get the feedback how they're doing, what they're doing and I think maybe if they had that kind of feedback it would help them.*

Some examples were given of educating audiologists and medical professionals about CI. For example in Australia, the user group, CICADA, is involved:

> *I think in Australia, there's been a considerable amount of work being put into training audiologists to refer people on for cochlear implants…… we started a programme where our cochlear implant audiologists will go to some of the Hearing Australia centres and do assessments there. So, they have been training up other audiologists in how to refer, when to refer. I think some of the other larger implant clinics are also working on this to train up other audiologists. Work on clearer guidelines on when they can refer people for a cochlear implant*
>
> *There is still also a lot of fear in relation to surgery. You know, that seems to be a big thing. There's still, I don't know, people who are in denial about their hearing loss - that's always that point as well. So I think all the audiologists need access to clear criteria on when they should be referring people to an implant clinic for assessment.*

For example, in the UK, the British Cochlear Implant Group works with the British Academy of Audiology to provide referral guidelines..www.bcig.org.uk

> *Audiogram and free-field is not an accurate or representative of how a person with hearing loss manages daily in their environment.*

It was recommended that the International Classification of Functioning, (ICF) from WHO was used:

> *So international classification, functionality... which is in guidance from the WHO is really important. Because it talks exactly about the things we are just discussing now. How we... functioning within society. What factors are important in functioning and audiologists or whoever is the health professional need to look at the person and the surrounding environment rather than just the person in the audiology clinic……. Which creates a false environment, which does not exist outside audiology. I would suggest that we look into the classification (ICF) and how it can be implemented and incorporated into the Living Guidelines.*

How to use the ICF - A Practical Manual for using the International Classification of Functioning, Disability and Health (who.int)

Variability in practice was an important issue not only across the globe but within countries, and the guidelines were felt potentially important in providing an opportunity to share guidelines and best practice, reducing variability.

> *It (Guidelines) will make finding and recommending a CI center for surgery easier: if they are all using the same or similar standards, less research on what one offers as opposed to another will not be necessary*
>
> *It has the promise of ensuring more adults will receive rehab after surgery and that reviewing and attending to patient outcomes will be part of the process.*

2. Is there anything missing from the Guidelines?

Person-centered care

There was a consensus about the **importance of person-centered care**, and patients being at the heart of decision-making, to ensure they were listened to, and provided with accessible information and that technology developments were user-driven.

> *There's going to be differences within countries. But there should be some universalities**, one of them should be person-centredness** and L was told she was doing fine and she's saying, I don't think I am doing fine. That means something failed and that means that the patient's voice was not respected and honoured and that should be a common thread, no matter where you live.*

If person-centredness is addressed, then there need to be different approaches, and this may be necessary for different countries, with differing cultures:

> *Even within nations/countries, there would also be different approaches between practitioners. I believe clinical discretion is equally important if not more important than a set of guidelines for the countries when it comes to differences of approaches……The best way we can contribute is to share our experiences and come up with a collective answer of how we would like the way we are approached and how the process is approached from the top to the bottom level.*
>
> ***Not everyone benefits from CI in the same ways**, transparency is also needed and realistic expectations managed. Having suchan open approach will benefit everyone.*
>
> *The (follow-up) appointments should be determined with the person-centered approach as each CI user is having different journeys*

Rehabilitation – what is it?

There was felt there needs to be a **greater emphasis on rehabilitation**, its lifelong aspect, while recognition of the challenges of providing evidence based guidelines for this.

> *I mean there is already a lot of information available, looking at surgery, fitting, I think. But we are missing a lot of information and guidelines on rehabilitation and aftercare.*
>
> *I hear from some people that they never see their surgeon again and there's no clear path of rehabilitation. So it would be really great if best practices could be, I mean that would maybe involve the hearing healthcare community and if these could be published in a medical journal. That is another big, open area, where people don't know what to do after they have their cochlear implant. They are left to find their own rehab programmes*

> *Counseling, technology training, information on accessibility in general and related to technology products used with daily ICT products (smartphones etc) peer support, signposting to associations (should be included)*

The challenges of management of the technology itself in everyday life was an issue that was considered essential in promoting good outcomes. There were lively exchanges in the chat room:

> *We need a discussion about what is and what isn't included in Rehab. Rehabilitation needs to include assistive devices, accessibility and technical assistance with technology.*
>
> *Sometimes I think for audiologists the word accessibility is not understood. We are fixed, right?*
>
> *CIs come with a box of technology -- even the brightest people don't know what to do with the assistive tech in the box.*
>
> *I can attest to that!*
>
> *And the minefield with which smartphone connects with direct streaming etc!*
>
> *Well yes, they think we are all IT specialist!*
>
> *We needed much more patient/user input to the design and tech process in the development of the tech.*
>
> *Audiologists now have to be Bluetooth experts too!*
>
> *The amount of technological input added lately needs to be FUNCTIONAL rather than just adding features just because "Why not?"*
>
> *Some of the assistive technology is so hard to use that I'm still struggling with it as a user after 8 years. There's no hope of the clinicians staying on top of every brand's products.*
>
> *Industry can help with this..*

Inclusion of counselling and psychological support

Hearing loss in adulthood has a huge emotional impact as a result of its impact on communication, on relationships and employment. The restoration of hearing by CI, while not full restoration, provides another huge change in life and an emotional challenge which is not often addressed and this became a major talking point:

> *The point I wanted to make was, I myself ended up needing psychological support because it was not provided by the National Health Service in the UK. And I met several cochlear implant users in my previous role who leaned on me to provide that support because they were not getting it in their own countries. I think when we talk about rehabilitation going forward, I would really like to see it separated because rehabilitation, I feel, is making sure that somebody's device is working. Making sure they are performing in terms of outcomes. But what are the psychological outcomes? Are they measured? I am not quite sure.*

> *Topics such as the fear or expectations by candidates could even be (addressed by) counselling, through the psychotherapeutic route.*

There needs to be the recognition of lifelong care:

> *Really the first is that the guideline summary at the moment just covers rehabilitation shortly and I think you have to strongly emphasise that the patient is life long, it can be a 100 year process (where an infant implanted)*

Peer to peer support

The issue of **peer-to-peer support** was one that was referred to frequently and considered important to be included in some way. Several examples were given where this was provided in groups for adults and where it was valuable, although **it was suggested care is needed and that they need experienced moderators and guidelines**. Some of these groups provide useful information material, from the user's perspective. A suggestion is that we gather these as available resources online and information on these groups in different countries, to increase accessibility.

> *I think that nothing is more powerful than being able to talk with those who can relate to the experiences and also it gives them the equal... to be involved to chat rather than being talked down at by a professional. ……… So I find that when talking to peers find out more about what the capabilities are of cochlear implants and what accessories can do... so we pick up tips that we would not get from hearing healthcare professionals. That is why peer support should be integral in the Living Guidelines where there needs to be a system in place that people can be connected to their peers across different stages.*
>
> *I think the volunteer support group can help a lot just in encouraging people to go ahead with an implant. Often allay that fear that people have about going ahead, just reassure them that it is all going to be OK and it will work and there is help available afterwards.*
>
> *But in the case of adults, it is very important to carry out this project because many write to me saying that they feel alone. That they don't know where to go and that their deafness isolated them from the world that they knew.*
>
> *One of the things that I found is a great barrier when it comes to the cochlear implant journey is (lack of) peer-to-peer support which has already been brought up in the chat box in the previous comment. I think... where the clinics and the audiologists should make the effort to connect someone, like a person who is going through the assessment stage to be connected with a cochlear implant recipient or even more than that, like as a recipient, they need to know that there are other recipients in the area. They could set up their own peer support network.*
>
> *Peer support may be the key for people, perhaps even more than psychological support*
>
> *Audiologists are very overworked people they do not have enough time to provide support for the emotional side of deafness. Need clinics and volunteer support groups. Need to provide guidelines for groups.*

> *Peer support offers safe space and place where you can ask any question you would never ask hearing care professionals. Also, peer support means others are walking in your shoes, they get it. Simply as that*
>
> *I agree also with S that psychological help is necessary for some clients and should be implemented as part of the assessment*

Understanding the impact of hearing loss and the transition after CI … which also affects the family:

> *Basic guidance must be provided for CI users and audiologists need to understand daily living with hearing loss.*
>
> *I agree S, mental health support is absolutely something that is needed to help them navigate through all the different emotions and feeling they are experiencing*
>
> *Yes, peer support is very important, as a peer, you can train and support CI-users and candidates before and after implantation lifelong*
>
> *Professional accompaniment is important, but also that of support groups, without it we walk alone without knowing where to advance, losing valuable time.*
>
> *In Mexico, some professionals do not believe that this is important, but great results have been seen when working as a team with the family and the patient, creating adequate and safe environments.*

Parent and caregiver support was also considered important – CI affects communication and roles in the family:

> *The whole family around the CI user should be considered in rehabilitation. Relationships and roles change after CI*
>
> *Absolutely @R - the dynamics can change so much post-CI*
>
> *Parent / Caregiver support also is important for families*
>
> *I think we need both peer and professional support. I'm currently supporting four families (parents) who are not even considered to be part of the CI process. Sometimes, the non-implanted are overlooked.*

Peer groups were considered important at all ages; the Conversation included three young adults, implanted as children, who considered it vital to be included in such a discussion, from the point of view of lifelong care:

> *I think peer support is one of the things that is valuable to young people from the sense of being able to connect with each other. And you know, one thing we talk about is growing up, for those of us who have had a cochlear implant at a much younger age and our parents made a decision for us and we are now at a point where we don't really know what we need to know, right. And so that's why in some cases things were put in place for me and now we have to think about what is needed on our journey with upgrades and everything else so. That is why it is good to have peer-to-peer connections...*

> *I think what is clear to me is that we don't have a clear pathway for young CI users as they become adults and where they transition from being cared for by their parents, having every need addressed, to when they become adults and have to start looking after themselves. And I have been staggered when talking to young people about how little they know about their own processes or own implant. They don't even necessarily know what they've got in their head, or anything about how the devices work, for example. That makes it very difficult for them to explain to anyone else how it works.*

Financial burden

For many countries, including developed countries like the US, **the financial burden can be significant and may be unexpected.**

> *What I feel is especially from the Indian perspective we also need to talk about the financial implication. One is getting the implant. But after getting the implant, talking about the accessories and the upgrades because that is a huge on-going cost, which they will need to factor in. So that is something, you know, I feel that it's important to say it out loud right in the beginning, so that the family and the recipient knows what the journey is going to be.*
>
> *The definition of profoundly deaf is critical to enable a patient to get approval for funds. The audiogram is no longer the acceptable criterion.*
>
> *I am contacted by people from other countries, especially recently from Iran, where there are children who have had implants and their families have been still paying off the surgery and everything but then if the processor was lost or for some reason it's not working they don't always have the finances to fund repairs and replacements. I mean, it's not good practice to be running implant programmes if they are not financially supported. You have an implant and then lose the processor, then it defeats the whole purpose. So, that is such an important thing, just to make sure that it is well supported. You know, not just for children, for adults as well, so they can continue to hear. So... very important.*
>
> *That is an important point.* ***The ongoing cost was a surprise to me. That should be explained upfront***
>
> *Unfortunately, companies push out upgrades and phase out repairs for older devices which leaves families stranded in terms of the financial strain because then they can’t upgrade but the company has phased out repairs for older devices so they are lost at sea on how to proceed.*

In Europe there are countries where users are not able to cover the costs of repairs.

It is also my experience that there are huge differences between countries concerning after-care, concerning upgrades and so on. In some countries it is every five years. In others, it is every seven or every ten years. In other countries, there's even no upgrade.

Finances are a huge deterrent for adults to go for CIs, as funding for adults is not available here

3. *How would you use them?*

There was little time for points 3,4,5 specifically; these issues which will be followed up, but participants were enthusiastic about looking at how they could use the guidelines to improve awareness, access, and provision. They were keen to support their implementation.

Users can participate mainly by spreading positive experiences, practical advice, explanations of what it's like to live with CI. Depends what is the level of knowledge about CI from users.

Will these guidelines, once they are set out, be actually implemented in the countries in a way, a person-centered approach is taken?

4. *What would the advocates need to support their use of the guidelines?*

Two brief comments – this issue to be followed up too.

Talking points for consumers

Talking points for hearing health care professionals

Summary

There was a huge support for the opportunity offered by the Living Guidelines project for raising awareness of CI globally, educating and sharing good practice and reducing variation in provision, and raising awareness of the importance of lifelong services, and of the range of issues to be covered by "rehabilitation." There was a consensus of the potential usefulness of the Living Guidelines for advocacy work.

Key messages:

- Lack of awareness remains a huge issue
- Variability in practice
- Those with hearing loss needing information to advocate for themselves and others
- The value of person-centered care, an approach that is gaining recognition in other fields of health care, and also in audiology.
- The crucial role of peer-to-peer support, but needs moderating and guidelines

- Rehabilitation needs to include more than listening resources and technology management and recognize the counselling role in therapy
- Managing the technology is challenging – more user-led participation in development required
- CI advocates are keen to use the Living Guidelines project and outcomes as tools for advocacy work in awareness raising, and the improvement of CI services globally, with a reduction in variability of access and services.

In the context of the Literature Review, this is challenging, but there is a huge opportunity for the Living Guidelines project to provide CI user and family advocacy groups with a powerful tool for their advocacy work and to provide an opportunity to make their voices heard.

The chat room was full of such comments and there was an enthusiasm for meeting again to discuss specific issues.

> ***This is a fantastic discussion to have. I am really happy to be here today.***
>
> ***Thank you for organising this.***
>
> ***I look forward to seeing how this develops.***

Note:

Sharing resources: A proposal to share what advocacy groups are doing and providing to be made available on www.ciicanet.org

13 July 2022