

## **CIICA Conversation: Adults with CI talking about the Living Guidelines Project 4**

**12 December 2022**

**Facilitators:** Leo De Raeve, Belgium, Chair CIICA

**Observers:** Sue Archbold, CIICA; Members of HTA who are leading the Living Guidelines Project.

Participants: 14 users of CI; 2 family members, 2 Audiologists/Researchers, 3 Advocacy leaders. Several participants have global leading roles in advocacy for hearing care.

Live captioning was provided. CIICA Conversations last for one hour and are not recorded.

Participants were from 9 countries: Australia, Belgium, Finland, Germany, Netherlands, S Africa, Switzerland, UK, USA.

Apologies received from several people who have previously participated.

Some participants sent further thoughts, which have been included in this summary. The Chat Room was busy and these have been included in this summary, which used the transcript. There was a great deal of agreement amongst participants:

***I found that what others are saying I would say myself!***

### **Framing the Conversation**

Prior to the Conversation, participants received further 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.

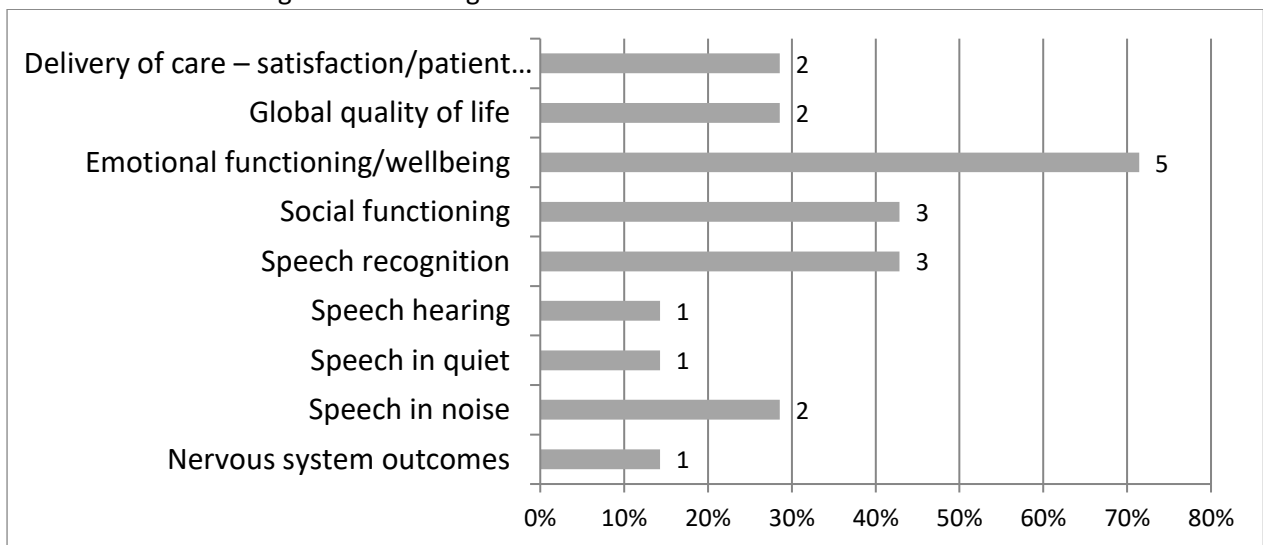
HT Analytics, the Australian group employed to manage the project, published the Guideline protocol on Prospero, which is an international register of systematic reviews and the review is underway. They observed our last conversation and this fourth one to gain insights into the issues important to CI users.

Leo began by reminding us of the topics that emerged in the first three CIICA Conversations on the topic:

- Lack of awareness remains a huge issue
- The hearing journey especially from hearing aid to CI needs guidelines to ensure timely referral
- Those with hearing loss need 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 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
  - CI advocates are keen to use the Living Guidelines project and outcomes as tools for advocacy work in awareness raising
- There needs to be clear, correct, short and accessible resources

The information about the results of the short survey undertaken of participants by HTA is shown below. Although a small number, the most important outcome for them was emotional functioning and wellbeing:



For this conversation, HTA asked for comments on their recommendation for Q8

- For adult CI users with severe, profound or moderate sloping to profound sensorineural hearing loss, which outcome measures are most meaningful to patients to assess for improvement with CI?

Their Draft Recommendation:

- Hearing specialists should evaluate **global quality of life** that includes social-emotional functioning/wellbeing.
- Hearing specialists could also evaluate speech recognition in quiet and in noise.

And HTA's draft recommendation for Q9:

- For adult CI users with severe, profound or moderate sloping to profound sensorineural hearing loss, what measurement tools and/or questionnaires should be utilised to measure patient outcomes?
- How and when should professionals use the measurement tools and/or questionnaires?

Draft recommendation:

- Hearing specialists should use the **Nijmegen Cochlear Implant Questionnaire (NCIQ)** to evaluate global quality of life (including emotional functioning and wellbeing) in cochlear implant users with severe, profound, or moderate sloping to profound sensorineural hearing loss.

- The NCIQ should be administered before cochlear implantation and then at least at 6 months and at 12 months after activation of the cochlear implant. Leo gave a brief overview of NCIQ (see link at end)

Participants had also been asked to think prior to the conversation about the assessments which were used as to whether they were useful or not and what assessments they would like. Leo facilitated discussion on these issues before returning to comments on the draft recommendations.

## **Issues arising from the Conversation on Assessment**

### **What assessments are important:**

#### ***Speech in noise***

There was agreement that speech in noise testing is important, and useful to the CI user, reflecting the challenges of everyday life:

*Speech in quiet is not as important as speech in noise. Life is noisy and this is where our scores really matter.*

*We had the testing in quiet and in noise - .... 95% in quiet – wow! The moment we put in noise, I just gave up....*

*Yes, speech in noise is definitely much more important because that replicates real life.*

*I have had my implants for 8 and 6 years, and speech in noise testing is quite a recent thing for me in my hospital. It's getting better and better, so I am happy to listen to sentences with noise behind. .... you can see measurable progress.*

#### **Purpose of assessment: understanding why**

There was a useful discussion about how important it is for people to understand why assessments are taking place in order for them to fully participate and gain value from them.

*There needs to be a balance between outcome measures which are important to the professional to monitor progress, and those that are important to the individual to their needs, but both need to understand the why for each other.*

Assessments can be used for disability benefits – to provide tests done in ideal conditions does not give an accurate reflection of everyday functioning.

There was also discussion about who needs the test? The user participants felt that it was really helpful to understand and see their own progress, especially when progress was slow or not easily evident:

*I feel like personal progress is important to know.*

*As a user, I have no way of comparing my own results and progress properly. I would like to know that I am getting the best possible results I can from the technology.*

However, often people felt that the tests were being done for the clinic's benefit – collecting data – not to improve the user's performance. This could be demoralising, especially if progress was slow or again not apparent, and when the testing apparently had no relevance to someone's real life. Seeing progress is encouraging for the user to continue with consistent wearing and practice.

*Most of the testing in hospital seems to be done for the hospital's benefit, not mine. I want the best results that I personally can get from the CI, not just a result that is good enough for the audiologist.*

*I found the whole process quite demoralizing because it was not practical for me in any shape or form and demoralizing that I could not tell the difference between cat and dog... nothing felt real about what I was tested on.*

*If I understood better the relevance of the different outcome measures, then I would have understood when I went back that I was actually making progress on things that mattered, rather than random words in the booth.*

*When I (surgeon) see these scores it gives me an idea how people are progressing and what the focus of auditory training should be next. .... Sometimes scores can drop – and people will have stopped auditory training so ... you are doing well, but maybe we need to keep doing auditory training in the long term to maintain a better result.*

There was seen to be value in collecting data so that people could then see progress against others and know how they were doing; some disadvantages to this too.

*If the data from the apps can somehow flow into the data that everyone is collecting worldwide then we can sort of get a better idea of how your progress is going.*

*Online, all of the tests can be global and the database would be fantastic. ....I can test myself and I continually keep testing myself....*

### **What is quality of life?**

The topic of quality of life was one for this conversation and its measurement. The question asked of HTA? What is the global quality of life?

*Global quality of life is broad definition I use the World Health definition covers it in this context, so individual's perception of their position in life and their context, the culture and value systems in which they live and in relations to their goals, expectations standards and concerns, so it's very broad, it's a broad definition to cover the broad domains that the NC IQ measures it does include social emotional functioning and wellbeing.*

Participants went on to give their own definitions of quality of life, with confidence being a common theme:

*To me, quality of life is more than just hearing, although it is important. It is the whole package of being able to communicate and being included, gaining independence.*

*What do we mean by quality of life? For me it means my ability to hear easily in different environments without effort... because it feels like if I feel like I am hearing well it inspires confidence. And I am more able to just be myself you know not feel like I am having to worry that I am not hearing everything. Quality of life to me is how confident am I in my hearing ability in different situations.*

*Every little improvement in hearing improves my quality of life. ... improving the quality of life doesn't improve the hearing.*

*It's about confidence in different situations.*

*We know confidence should generally give us better quality of life because we get more confidence in ourselves to ask for the services we need.*

### **Challenges of assessing changes in quality of life**

*Quality of life it's going to be very personal and individualised..... I wonder if it (assessing) could start from asking what is important to the individual, then **how is it that hearing is getting in the way of achieving those goals**, because hearing is not the only factor in the quality of life.*

*Of course the whole point is to improve quality of life but quality of life is very complex thing and I always worry about these routine general scores where somebody could have had a hip replacement during the year and their quality of life is much better but it's got nothing to do with their cochlear implant.....quality of life should have a listening component.*

*To make some global quality of life that does not seem to have any real tangible measurement, something you can compare at base level, I don't think you can get that.*

*We can't have a global quality of life but we can have a global template. ... not a global measure but a global template that takes into account what is important to that particular individual in terms of quality of life.*

*I came across what is called the "What Matters to you" movement. It could not be more personalised – it's what matters to you and what matters to you now, because it will change over time. .... And we are going to update it as life changes. (link below)*

*We are not a homogenous group – everyone will be starting from a different point, depending on the cause of their hearing loss, how long since lost hearing, if they had an implant as a child and so impacts on life will be different. Are we reflecting that sufficiently?*

There was noted by several people the danger of expectations – both too high, and too low – when given quality of life outcomes. The Nijmegen Quality of Life Questionnaire is recommended and others were recommended – see below.

## **Funding**

Funding for ongoing services was a major issue for participants. Often funding wasn't included for ongoing rehabilitation or for follow up appointments when programming had been changed or upgrades carried out.

*It would be wonderful if the follow up to significant mapping changes could be perceived as part of the original appointment. US insurance doesn't always cover entire appointment costs and its not cheap.*

*My insurance here in \*\*\* isn't willing to cover aural rehab so I'm filing grievances to fight for it, especially since they cover speech and language therapy 100% but the fact I require "hearing therapy" makes it non covered.*

*Aural rehab not covered in \*\* either.*

*Some implant programs are not well supported... no access to replacement or damaged processors, sometimes people still paying off the surgery costs over time.*

There were several suggestions that online appointments or testing schedules could be time and cost-effective and provide ongoing monitoring for the user.

*Develop more apps and testing schedules that we can do at home if you don't have the time (or funding) to professional appointments., but maybe the apps can be developed with a view to looking at how the professionals are testing so that you can get a comparison.*

## **Assessments: managing the technology and changes in programming**

There were many comments about managing the technology and that people needed to be trained and have confidence in this to ensure progress and assessments would be appropriate. This need not be done by highly qualified audiologists, and peer groups can have a role.

*I am using this new gadget which is driving me nuts to be honest, it's going to take some time to get used to it.*

*What I see is recipients needing to be educated in the use of their device as well to get the best results. What I see is a good proportion of recipients lacking in confidence about changing the basic parts, also not understanding the different programmes.... they can do better in noise if they know how and when to activate the different programmes, or use assistive listening devices.*

*CI Coaches are perhaps a more necessary part of the future of Cis, having people trained up as coaches, and working with the professional team to give people confidence.*

## **Listening to people: are assessments and appointments responding to need?**

There was a shared experience that people had not felt their needs were listened to so appointments and assessments weren't always appropriate. It was felt that people needed longer term aural rehabilitation – and also needed their personal needs to be addressed.

*It important to have longer term auditory skills training*

*Nobody ever sat down and explained what to do except listen to an audiobook or listen to a YouTube video and stream it. .... They gave me Angel sounds, but no one told me what to do with it or what features were best for my struggles.*

A major issue was not having follow up appointments when major changes had been made, or when major changes in performance been observed.

*When I tried to convey my concern about waiting an additional year to be seen and re-evaluated after a significant decrease, I was told I pay too much attention to the scores and I shouldn't let them impact on me. Instead I should just keep practicing and doing what I had been doing. So it became clear to me that I was going to need to do a better job of self advocacy.*

*I went in for mapping – because of COVID it had been quite a while since I had been there. My thresholds had dropped off quite a bit, so we made several adjustments to my cochlear implant map to try to get it back up. But then here was not offer of a follow up appointment..... they don't assess you right after changes because you have to get used to the new map which makes sense. But then in my case I was going to have to pay a bunch of money to come back to make sure it's a right map. So, for the last year, I have been wondering if the changes made were actually an improvement or not. ...it would be nice to have a measure, personal progress over time in a way that works for the patient not the hospital.*

*I grew up in a south Asian family where we have big family gatherings every weekend and I was really frustrated with background noise when everybody is chatting at the same time. I went to a mapping appointment and said I find it difficult in noise. Its been a week now, and its been a lot quieter, but I feel a lot of pressure that I would be bothering thme if I contact them. They ask us to come back in a year's time, but don't check to assess ud if we are satisfied, maybe in a month or 6 months.. its always after one year. Sometimes we feel we have lack of confidence to reach out if we want some changes.*

*After listening to comments, I am wondering if the testing that I was given really was more for the clinician than for me. ... I had a significant decline from 70% to 20% in noise. But still maintained good score in quiet. ... my next appointment was supposed to be for 2 years... I said how can you send me home with a significant decline and tell me to do more of the same when I am declining.*

*Adverse events follow up by clinics must be addressed in a timely and appropriate manner. I see many comments on Facebook (CI experiences) from people who are in pain or have had a*

*illness which they say is due to implantation and I am not sure they are getting their issues addressed or investigated thoroughly.*

### **Family quality of life**

Hearing loss affects the whole family, and the fitting of a CI changes the family dynamics and relationships, and hence family quality of life – parents, partners, any significant others. Improved communication abilities, confidence, independence all change the way in which the family functions. This is often ignored.

*I think we need to do more to build in wider family input to “real life” outcomes for adults.*

*From a family member point of view it is being able to have a conversation and knowing how to do it with her., so that it flows the way it does with hearing people. So my mom and I today can in person talk as long as there is light, and she can read my lips. We can talk fluently so that people who do not know her do not think she is deaf.*

*Some of my friends think this cochlear implant is a magic thing you put on and works perfectly. She is a good user, but she (my mom) continues to coach her environment (us!) relentlessly how to talk to her. I think that if we were able to almost show how she taught us what to do I think that is very helpful,*

*I think there is a big measurement from family measurement, can I talk to my Mom on the phone, we live in different countries , I can do all of these things, I can even go to the movies with my Mom.*

*If I were to choose one thing, its my ability to communicate with my Mom and I remembered very well how it was just before the cochlear implant versus just after and for me because I didn't have to go through the surgery it was for me like magic once she got them.*

*I think coaching patients, first of all, to be relentless and feel comfortable for them to coach everybody around them because I don't think that it's easy to do that. By empowering them to do it and giving them confidence to do it.*

*My wife's quality of life has improved because mine has improved.*

### **When to assess quality of life impact of a CI**

There was general agreement with this statement:

*I think 3 months can be too soon to see changes. It depends on the person – I would say at implantation to set the benchmark, then 6 months later, then a year and at 2 and 3 years. I was born with a profound hearing loss so it took a longer time to benefit.*

### **Summary of key points:**

- Emotional functioning and well being very important to CI users, but complex to assess
- Quality of life is diverse, individualized



- CI users definitions of Quality of Life are different to that of researchers
- The purpose of assessments needs to be explained to CI users and prospective users, and they need to be meaningful
- Assessments can support device monitoring, programming needs, and rehabilitation needs
- Assessing speech in noise is important to reflect challenges in real life
- Assessments need to have a longer time frame
- Adult CI users are a diverse group and assessments should reflect this
- Changes in assessment should be followed up in a timely way
- Family quality of life should be considered
- Funding is required for ongoing assessment and monitoring
- CI coaches and peer groups have a role in ensuring ongoing progress

As usual this Conversation was wide ranging and very informative; we plan to summarise all four conversations into one summary and then into a one-pager to be used for advocacy work. Our Conversations have had an impact on the Living Guidelines Project: thanks to all for their input and to HTA for listening!

### Comments on the recommendations

Attached the redrafted recommendations.

*That was self advocate – I didn't know what I didn't know.*

*There is always so much more to say, but I will leave it there for now!*

### Useful information

What matters to you? <https://wmtty.world>

<https://advancingaudcounseling.com/what-matters-to-you/>

Nijmegen test paper:

JOHANNES B. HINDERINK, MD, PAUL F. M. KRABBE, PhD, and PAUL VAN DEN BROEK, MD, PhD, , (2000) Development and application of a health-related quality-of-life instrument for adults with cochlear implants: The Nijmegen Cochlear Implant Questionnaire Otolaryngology– Head and Neck Surgery, vol123, no 6, P 756-765