

CIICA Conversation: Adults with CI talking about the Living Guidelines Project 3

24 October 2022

Facilitators: Leo De Raeve, Belgium; Michal Luntz, Israel; Emma McAuley, Ireland

Observers: Brian Lamb, 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. Four participants were both CI users and professionals – two surgeons, one audiologist and one psycho therapist. 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 12 countries: Australia, Belgium, Canada, Finland, Germany, Ireland, Israel, Netherlands, S Africa, Switzerland, UK, USA.

Introductions:

Leo De Raeve is Chair of CIICA, Director of ONICI, Co-Chair of the Living Guidelines project, Scientific Advisor to EURO-CIU.

Michal Luntz, MD, is Surgeon-Scientist in Otolaryngology and Implantable Hearing Solutions, and CI User from Tel Aviv, Israel. She is President of the Israel Society for Auditory Research and Board Member of Bekol – the Israeli Association for Hearing Impaired.

Emma McAuley is an Audiologist in Ireland, and received her implant nearly a year ago.

Attendees also introduced themselves via the chat room and beforehand.

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 the conversation to gain insights into the issues concerning CI users. Leo began by sharing their overview of the process, reminding us that there is very little for Step 6, which is **Patient relevant measures for healthy ageing**.

HTA would like CIICA support before reviewing the recommendations with the Task Force to have a truly patient-centred approach to the development of the guidelines. Question 8 is: 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?

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

- Lack of awareness remains a huge issue
 - The hearing journey especially from hearing aid to CI needs guidelines
 - 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 need to be clear, correct, short and accessible resources

He then went on to share the plan for the Conversation:

1. Michal sharing thoughts on person-centred care as a surgeon and a CI user.
2. Emma sharing thoughts about effective rehabilitation as an audiologist and user
3. Leo asking about what outcomes are important to users themselves – and their families.

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

1. Person-centered care

Person-centered care is a topic that is growing in recognition in many domains as being key to successful outcomes from interventions. However, person-centered care takes time which is challenging. The need for person-centered care has been repeated in our Conversations – or rather the lack of it. For example, in our Reimagining Rehabilitation Conversation, no one had been asked what they would like or needed and in our Tinnitus Conversation, no one had been asked about Tinnitus, which would impact on mapping. See these summaries at [CIICA CONVERSATION: Adult Services after CI: Reimagining Rehabilitation – CIICA \(ciicanet.org\)](#) and [CIICA CONVERSATION: Experiences of Tinnitus and CI – CIICA \(ciicanet.org\)](#)

In this Conversation, contributors again commented that professionals need to work WITH the user/recipient and that person-centred care is rare in CI programmes.

Another point regarding successful outcomes & rehab for CI recipients, is that the audiologist NEEDS to focus more on listening to and working with the CI recipient, because as we said every person is different and their CI journey will progress at different rates.

Before referral: awareness and information

From hearing aid to cochlear implant involves a huge change and transition as part of a hearing journey; during this transition there are different opportunities for person-centred care. This involves both the patient and the hearing care professional. There was an emphasis that before and after implantation, people should understand the process and all information needs to be accessible and understandable. People do not take in information when they are stressed; the need for written and accessible information was considered vital if people are to be able to make an informed decision.

There was a discussion about the challenge of the process from hearing aid to CI – and this was seen as a major issue to address. Several attendees had waited a long time to go for a CI – 18, 20 years – and wished they had decided to have a CI earlier. There was a discussion about how to change this, knowing that the shorter the length of deafness the better the outcome likely to be.

“This is the main problem we have to discuss; we have to do it responsibly because it’s a big step in the life of a CI user.”

“It’s a big step hearing aid to cochlear implant, if you have to have surgery, that is a really big step and there is a lot of fear and anxiety around.”

“Hearing aids to cochlear implants is a TRANSITION and needs to be treated as such.”

“If cochlear implants are introduced earlier into the hearing journey it may give more time for people to learn about them before the pressure to make a decision.”

“It’s imperative that CI needs to be included on the hearing health continuum.”

Peer group support: decision making

Several people mentioned the importance of meeting others during this time – learning about CI in a group, and meeting others with CI to find out what is really involved, to have realistic expectations and overcome fears or misunderstandings, for example what the technology really looks like and how to manage it daily.

“I had to try to build this peer support for myself because ENT and clinic audiologist weren’t really concerned about peer support unfortunately.”

“It’s important to help them understand that they won’t hear exactly like they used to hear. They need to know that there is going to be work involved. “

Setting realistic expectations was important – high but realistic – and this is challenging. *“expectations that you get switched on and hey presto are the recipe to disappointment.”*

“In fact a CI has a lot of limitations, compared with a normal ear – yet somehow, the brain overcomes a lot of it.”

“When they meet others, the decision comes. Don’t press them – the decision will come from them alone. You need an atmosphere like over coffee and a group. It is more than face-to-face, speech from doctor to patient.”

The groups also need to include significant others and family members; hearing loss and its management affects the whole family and:

“The patient should not assume that his or her significant others understands the way they need them to.”

“I had no idea what the doctors were saying. And my family members would be with me and never passed on the information that I needed because they didn’t think it was needed. “

Cochlear implantation not only impacts on the person receiving it – increased confidence in communication and independence can alter the family dynamics and people aren’t often prepared for this:

“Relationships and dynamics in the family can change a lot after CI.”

Different people want different information to make the decision:

“I have a science background and what motivated me was seeing an audiogram outcome for someone with a CI and then I could see the difference – I wanted that.”

2. Rehabilitation

There was much discussion about the range of progress and examples where people had made excellent progress, better than expected, but others really battle to hear and make progress.

“So the level and standard of care needs to be adapted to suit each individual and the rehab expectations and journey needs to be managed appropriately for the CI recipient, and not the CI recipient being expected to do the rehab as prescribed. Quality time spent with the CI recipient at the early stages of the journey is crucial in my opinion.”

Key to progress was listening and listening – and persevering. The point was made about training the brain to use the new hearing in communication and with confidence; a whole range of tools was used – and examples given of developing rehabilitation in everyday life. Listening to TV with and without subtitles, to TED talks, to audio books .

The point was also made about the importance of good mapping – ensuring that mapping changes with progression. Some people have very little mapping or rehabilitation and this was a concern. Our large survey confirms this: see [Sharing initial data from our survey of adults with CI: thanks to you all! – CIICA \(ciicanet.org\)](#).

“Most people don’t know how good they could be with rehab. ... That’s a problem. We have a sports car in our head but many people are going with the speed of the bike.”

A discussion about how to help those who are struggling – giving them more rehabilitation, and the role that peer mentors could have in this, due to shortage of professionals.

There was discussion about the provision of rehabilitation and overcoming staff and funding issues: the point was made that providing good rehabilitation costs comparatively little money and can make a huge difference. For example, providing intensive rehab at the beginning:

“We get 80% back to work after three months. Even to work in communications, like doctors, teachers and so on.”

“We have to show the patients, and the insurance and the clinics that we can win with the best rehab.”

“The money is not always invested in the best way. That’s a problem. ... we have to look at what we can get with the minimum of cost and the maximum of benefit.”

However, there was consensus that many people were successful using tools such as audio books at home, making sure that they worked at learning to listen in everyday life, using all opportunities.

The importance of music : *“finally to be able to enjoy it with the cochlear implant – that was success.”*

Also mentioned was the range of patients’ needs – another argument for the need to be person focussed: for example people who have been deaf for a long time, who have tinnitus. For this you need a multi-disciplinary team.

Rehabilitation was thought to include not only developing listening skills, but should address the psychological needs of the CI user through the tremendous transition on their hearing journey:

“It is astonishing that the range of mental health concerns are not being addressed whilst the rapid CI process is being done either to themselves or to children. It is a massive transition. Somebody mentioned the jump from hearing aids to cochlear implants is massive. I don’t feel it’s being addressed.”

Counselling, or time to discuss the impact and to adjust to changing communication skills and needs is rarely included in rehabilitation programmes, but is a consistent feature of our Conversations between users and in peer support groups. A focus should be giving people confidence and this includes managing the technology.

There was mention of learning how to manage this complex technology:

“we are offering workshops for explaining the use of technology.”

“ this is where CI manufacturers can help!”

“ the CI companies rely on mentors and ambassadors to do this.”

Leo provided the WHO definition of rehabilitation:

“Rehabilitation aims to optimize everyday functioning of those with hearing loss to ensure that the person reaches the best quality of life at a physical, functional, social, emotional and economic level.”

3. Meaningful outcomes for users and their families

If that's the goal, how do we measure everyday functioning? Evaluating the outcomes which were important to users and their families was seen as vital – in providing meaningful information to those thinking about CI, and to monitor progress to inform rehabilitation and mapping programmes.

“Number one important thing is to decide on how to evaluate outcomes. “

However, what success looks like was thought to be different for different people:

“Another issue is the patient's perception of success. You know, this is personality dependent.”

“One person's good outcome might be another person's bad outcome.”

Even if realistic expectations had been set – they can change over time as progress is made:

“Sometimes people are getting really good scores and yet their own perceived impression is that they're not doing very well.”

Given the impact of CI on the whole family:

“Maybe an outcome measure for the effect on the family/significant other?”

Why measure outcomes?

“Good outcome measures can be used to inform mapping as well as counselling and rehabilitation needs – so important.”

To do this outcomes were needed to be accessible and understandable to users, their families, and funders and public health decision-makers. There can be a discrepancy between clinic scores and what is happening in everyday life:

“Information can still get missed when good scores are achieved. It's possible that other people assume that all the information is being heard and absorbed... there is still a cognitive delay and extra load.”

“Listening in noise is another thing entirely. While I hear so much more now, I think I am still missing a lot but I don't know how much. Its not just about what we hear but the cognitive listening effort and recognition.”

“As an audiologist, my audiogram and speech scores do not represent real life experience. “

Mention was made of Categories of Auditory Performance (CAP), developed for just this purpose to measure progress in everyday life, and now in many languages. It can also be used for people to monitor their own progress; it correlates with clinic-based measures of speech perception, which is the foundation of progress.

There were comments about not being given objective measures which would be helpful – such as aided thresholds which give an indication of the change in speech perception from hearing aid to CI.

“Patient-perceived outcomes are important. We want them to feel that they are doing well and sometimes peer support mentors can help build that confidence. ”

Measuring the person and family centered outcomes, has been called Measuring the Immeasurable. For example, one attendee:

“Once I had been implanted I felt a weight lift off my shoulders. I had been in a dark, depressed place for very long. Suddenly I felt connected. I cannot measure that. I can feel it.”

“I agree with S that we should have a psychological evaluation before and during the journey of CI.”

In the first Conversation on the Guidelines it was recommended to look at WHO International Classification of Functioning, Disability and Health:

“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 \(who.int\)](#)

Summary

While this Conversation had three strands to it and therefore had a lot to cover, the Conversation reinforced and developed ideas that have been expressed in other CIICA Conversations and also ideas which are becoming more common currency in research, including health literacy, and patient activation (or involvement – not activation as in activating the implant!). See below for refs.

There were concerns that there are a number of good studies about patient expectations and outcomes that tend not to be captured by the standard database searches either because of the type of journals they appear in or because they are counted as "grey literature".

There were also concerns that most research looks at clinic-based measures and not at how users might define their outcomes in everyday life. While attendees queried why measures such as those of mental health, confidence, and isolation are not undertaken, there **are** examples of these being included and reported, but clearly not widely.

Key themes:

- CI needs to be part of the hearing journey with better information to smooth the transition from hearing aid: peer groups can be key to this to overcome misinformation
- The huge change and transition following CI needs to be recognized

- Person-centered care is considered vital for the best outcomes in real-life. Partnership between user and professional
- Regular mapping and rehabilitation is necessary for progress
- Peer groups have a key role prior to and after CI
- Significant others (families) need to be included in decision-making and rehabilitation and outcome measures
- Outcome measures need to reflect functioning and changes in everyday life and need to be understandable to inform decision-making by potential users and decision-makers and to inform mapping and rehabilitation programmes
- Outcome measures need to be “owned” by the CI user; perceptions of outcomes will vary

Useful information

See Brian’s October 2022 research round up at : [Research Roundups – CIICA \(ciicanet.org\)](https://www.ciicanet.org/research-roundups) which includes points about Health Literacy and CI :

Hübner, C.; Lorke, M.; Buchholz, A.; Frech, S.; Harzheim, L.; Schulz, S.; Jünger, S.; Woopen, C. Health Literacy in the Context of Implant Care—Perspectives of (Prospective) Implant Wearers on Individual and Organisational Factors. *Int. J. Environ. Res. Public Health* 2022, 19, 6975. <https://doi.org/10.3390/ijerph19126975>

Frances Rapport^{1*}, Sarah E. Hughes^{2,3}, Isabelle Boisvert^{4,5}, Catherine M. McMahon^{4,5}, Jeffrey Braithwaite¹, Mona Faris¹ and Mia Bierbaum (2020). Adults’ cochlear implant journeys through care: a qualitative study. *BMC Health Services Research*. 20:457 <https://doi.org/10.1186/s12913-020-05334-y>

Example of paper on quality of life:

Kevin J. Contrera MPH, Joshua Betz MS, Lingsheng Li MHS, Caitlin R. Blake MSPH, Yoon K. Sung MHS, Janet S. Choi MPH, Frank R. Lin MD, PhD (2016). *Quality of life after intervention with a cochlear implant or hearing aid.* *Otology/ Neurotology*. <https://doi.org/10.1002/lary.25848>

Interesting material about “patient activation”

https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/supporting-people-manage-health-patient-activation-may14.pdf

Categories of Auditory Performance – developed with children but works with adults! And widely used still in many languages. This is the original; Category 8 is now used: Use of telephone with unknown speaker.

Archbold S, Lutman M, Nikolopoulos T (1998) *Categories of auditory performance: inter-user reliability.* **British Journal of Audiology**, Vol 32 pp7-11.

Categories of Auditory Performance (CAP)

Name:

Date:

	Categories	Tick Achieved
0.	No awareness of environmental sounds or voice	
1.	Awareness of environmental sounds	
2.	Response to speech sounds	
3.	Identification of environmental sounds	
4.	Discrimination of speech sounds without lip reading	
5.	Understanding of common phrases without lip reading	
6.	Understanding of conversation without lip reading	
7.	Use of telephone with known speaker	