

CIICA Conversation: Adults with CI talking about the Living Guidelines Project 2

7 September 2022

Facilitators: Leo De Raeve, Belgium, Michal Luntz, Israel, Helen Cullington, UK

Observers: Brian Lamb, Sue Archbold, CIICA

Participants: 16 users of CI; 2 family members, 2 Audiologists/Researchers, 3 Advocacy leaders. Two participants were both CI users and professionals – one surgeon and one audiologist. 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 14 countries: Australia, Belgium, Canada, Finland, Germany, Ireland, Israel, Italy, Netherlands, Slovenia, S Africa, Switzerland, 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.

Helen Cullington, PhD is Professor and audiologist, University of Southampton, UK and Chair, British Cochlear Implant Group

Michal Luntz, MD, is Surgeon-Scientist in Otology 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.

Attendees also introduced themselves via the chat room and beforehand.

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.

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

Lack of awareness remains a huge issue

Huge variability in practice between services and centres

Those with hearing loss also need information to advocate for themselves and others

Financial burden of ongoing costs

The value of person-centered care, an approach which 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 (psychological support) in therapy

Include the issues of ICF

Managing the technology is challenging – more user led developments required

CI advocates keen to use the Living Guidelines project and outcomes as tools for advocacy work in awareness raising

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

1. Helen sharing the UK guidelines and their current revision
2. Michal sharing how she would use the guidelines for advocacy
3. Discussion on these topics and on how we could use them and what we needed to use them effectively.

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

1. The need for guidelines

The discussion highlighted once more the need for guidelines: examples were given where assessments in different countries produced very different recommendations. This applied to comparisons between high income countries too; and recommendations were influenced by funding arrangements.

After experiencing different recommendations: *“for the systems everywhere standardization would be helpful for everyone....I know its difficult when you factor in different policies.”*

Along with the need for guidelines it was felt important that they reflected person-centered care, as discussed the first Conversation.

The need for coordination in this way is currently being highlighted by the President of the American Academy of Audiology and there was a comment that it is much needed: *“nothing is going on in an organized fashion here.”*

“Adults are kind of left in their own ways.. the best they can hope for is to find the right centre, information and right people.”

“My hope is that the Living Guidelines will present a document that countries can bring back and utilise in a uniform way.”

There was substantial agreement that there needed to be two different guidelines:

“It seems like there are two things needed- guidelines for raising awareness and improving access, and guidelines for service provision.”

“I agree with N”

“I’ll second that comment about 2 different sets of guidelines...”

2. Sharing guidelines

It was felt helpful to share what guidelines there are, some of which are clearly useful. Helen Cullington share the British Cochlear Implant Group (BCIG) Quality Standards, which are currently undergoing considerable revision:

“our BCIG Quality Standards over the whole implant journey, the assessment, surgery, programming, rehabilitation support, we also talk about and have quality standards about staff numbers, qualifications, the environment of the clinic, for example access to language support in the waiting room. But we need to move on to evidence based guidelines and the living guidelines will have the advantage of being responsive to anything that comes up....”

The current ones can be found at: <https://www.bcig.org.uk/wp-content/uploads/2021/03/QS-update-2018-WORD-final-v2.pdf> . At BCIG you can also find the limited but useful registry which is collected annually.

Other countries have guidelines too – Germany, Australia, were some examples given, and Reinhard Zille sent the link <https://cdn.hno.org/media/2021/ci-weissbuch-20-inkl-anlagen-datenblöcke-und-zeitpunkte-datenerhebung-mit-logo-05-05-21.pdf>

Which gives:

Weißbuch Cochlea-Implantat(CI)-Versorgung (Überarbeitete 2. Auflage, 2021

White Paper on Cochlear Implant (CI) Restoration (Revised 2nd Edition, 2021 with Recommendations on the structure, organization, equipment, qualification and quality assurance in the care of patients with a cochlear implant in the Federal Republic of Germany Prepared by the Presidium of the DGHNO-KHC.

“There must be a wealth of information out there, it just needs to be collated, and all the best bits put in the living guidelines.”

However, it was agreement that the guidelines must be person and family centred:

“ we have some kind of guidelines in the hospital and in the process... but it is more from audiologist and doctors. Not for users.”

“the point of view of every guideline should be the patient and their significant others”.

It was felt helpful to link any standards or guidelines to **registries** although this is a long process. Switzerland is an example of a country where the national registry is open.

Guidelines being part of the hearing journey

There was considerable discussion about the Guidelines being a useful tool at the awareness and referral stages and that they could help overcome the problem of lack of awareness by hearing aid users as well as audiologists.

“We are all on a hearing journey...”

“I have found when I am talking to people who are going through the CI journey its like a barrier they face when they go to an audiologist they have been to for a long time and hearing aids don't work and a conversation about CI never came up until the person found out about a CI through other means...”

“There are many places where patients are being blocked about CI as an option. There needs to be a protocol in place then a patient has a certain degree of hearing loss It should be mandated that they bring the CI into the conversation. ... Then the patient can decide what would be the appropriate steps to take..”

“Yes if there was a protocol in place where somebody's hearing was around 60dB ... most of us only hear when its all gone. .. imagine the amount less of worrying, fear, trauma, that kind of stuff ... people would not be spending their time til hearing hit rock bottom.”

*“I really appreciate the perspective of a patient with a 60dB progressive hearing loss who **needs to know** what a cochlear implant can do, and how to obtain it. It would be such a relief to know that there is hope. “*

Moving forward: what is needed

The guidelines were considered very timely:

“The timing is perfect because the WHO came out, with the March 3 title (World Hearing Day) Ear and Hearing Care for All ... this is perfect timing to collaborate and coordinate the Living Guidelines with the WHO topic.”

“The explanation for the patient should be structured. What the patient has to know, they have to know everything, so we have to be very very clear.”

There were many comments that we need to make the difference a CI can make very clear, while also sharing the limitations.

“The information must uncover the untruths... (about CI)”

“We, the hard of hearing individuals, are 15% of society.”

*“The patient should be able to judge for themselves and we need to **empower the patient** with this information (in the guidelines.)*

“if the guidelines are short and clear we can use them in the public domain in the media day and night. As long, as they are very very clear and very correct we can feel confidence in them and stand behind them. “

“What might help is a one page bulleted “talking points” to make them helpful to advocates.”

“and to have them published..”

“yes they should be easy for the media to use”

“and we can translate them..”

“They need to be accessible to those with hearing loss and their families to be able to use them to advocate for themselves, to challenge professionals who are maybe barriers to referral”

A term came up – **“democratising the information”** which seems to sum up the conversation about accessibility and providing information to be used for advocacy.

There were comments about the sustainability of the guidelines: *“how can we ensure the guidelines are sustainable and kept up to date.?”*

Peer to peer support

Throughout the conversation, a major theme of peer to peer support recurred, which was so important we need to think how to include it. This was not seen as only patient to patient but to include the whole family who are impacted by hearing loss and the CI process.

“peer to peer support is fundamental as is an approach which incorporates the entire family.”

“Peer support is essential in my opinion.”

This can be really helpful when thinking about an implant and unsure about surgery:

“Meeting peer advocates really does offer reassurance and encouragement...”

“Maybe we can have a Conversation about best practice in peer support..?”

Summary

The group really valued these Conversations: *“it is a marvellous opportunity.”*

“I’m sorry I’m not too smart at the technology but glad I was there tonight!”

In summary:

- The guidelines are necessary to coordinate provision
- To ease the hearing journey especially from hearing aid to CI
- They should be family centred
- They should be clear and accessible
- There may be two: for awareness and for the process
- There needs to be clear, correct, short and accessible resources to use for personal advocacy work and with the media.
- Peer to peer support is hugely important: another Conversation