



LISTENING TO CI USERS AND FAMILIES

Assessments and their purpose should be clear to users and families and reflect functioning:

- “ Good outcome measures can be used to inform mapping as well as counselling and rehabilitation needs – so important.
- “ 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.
- “ 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.
- “ Speech in noise (assessment) is definitely much more important because that replicates real life.

The Guidelines are essential to increase awareness, access, provision and reduce variability in practice: CI advocates, users and families are keen to use these in advocacy work:

- “ 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.
- “ 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.

There needs to be clear, correct, short and accessible resources for the Living Guidelines to enable groups and individuals to use them for personal advocacy work and with the media:

- “ 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.
- “ Above all, it (Living Guidelines) is necessary for an individual to get/give/pay CI.
- “ Users can participate (in Living Guidelines) mainly by spreading positive experiences, practical advice, explanations of what it's like to live with CI.
- “ What might help is a one-page bulleted “talking points” to make them helpful to advocates.
- “ It seems like there are two things needed- guidelines for raising awareness and improving access, and guidelines for service provision.

Use the issues raised here for your own CI advocacy work.

There needs to be greater awareness of the impact of hearing loss (HL) and of CI:

- “ 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.
- “ How can the users self-identify and self-refer as candidate? I think most candidates do not realise that they would be candidates because no-one is telling them, they have no way of knowing.
- “ I think all the audiologists need access to clear criteria on when they should be referring people to an implant clinic for assessment.

Information should be “democratised” to enhance patient literacy to ensure users and families can make informed decisions, and be part of their own care and self-refer:

- “ We need to empower the patient with this information (in the guidelines.)
- “ We are missing a lot of information and guidelines on rehabilitation and aftercare.

For further information and full summaries go to: ciicanet.org/resources/living-guidelines-for-ci-for-adults/

CIICA. AISBL March 2023

CIICA was invited to provide the CI user and family voice to the Living Guidelines Project. This project (Living Guidelines | Adult Hearing) aims to address the significant under provision of cochlear implantation for adults. The project has created evidence-based guidelines for CI in adults and shares good practice.

CIICA held four Conversations on the project, with 60 participants from 20 countries, providing opportunities to comment on the areas of Rehabilitation and Outcomes. Following each conversation, a summary of the issues which arose was made, and circulated for agreement. This synopsis summarises the conversations and provides the key points important to the users and their families, and provides representative comments.



Outcomes important to researchers and users can differ: Quality of life outcomes, including changes in confidence, are most important to users and families:

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

Cochlear implantation should be part of the lifelong hearing journey:

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

Person and Family Centred CI Services are vital for the best outcomes in real life, and the family and significant others should be involved in partnership with professionals:

- “ 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.



Email info@ciicanet.org or visit www.ciicanet.org



The transition from HA to CI is much greater than recognised:

- “ 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.

Regular programming and rehabilitation are key to progress:

- “ . . . there’s no clear path of rehabilitation . . . people don’t know what to do after they have their cochlear implant. They are left to find their own rehab programmes.
- “ Counselling, technology training, information on accessibility in general and related to technology products used with daily ICT products (smartphones etc) peer support, signposting to associations
- “ 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.
- “ Nobody ever sat down and explained what to do except listen to an audiobook or listen to a YouTube video and stream it.

Rehabilitation should include a counselling role: coaching can be key:

- “ It’s astonishing that the range of mental health concerns are not being addressed . . . the jump from hearing aids to cochlear implants is massive. I don’t feel it’s being addressed.
- “ Mental health support is absolutely something that is needed to help them navigate through all the different emotions and feeling they are experiencing.
- “ Expectations that you get switched on and hey presto are the recipe to disappoint.
- “ Relationships and dynamics in the family can change a lot after CI.
- “ 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.

Peer groups have major role to play before and after CI; they need guidelines:

- “ Professional accompaniment is important, but also that of support groups, without it we walk alone without knowing where to advance, losing valuable time.
- “ Peer support may be the key for people, perhaps even more than psychological support.
- “ Audiologists 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 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 find that when talking to peers . . . 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.
- “ Peer to peer support is fundamental as is an approach which incorporates the entire family.

Assessments should have a longer time frame and reflect diversity of users:

- “ One person’s good outcome might be another person’s bad outcome.
- “ Sometimes people are getting really good scores and yet their own perceived impression is that they’re not doing very well.
- “ I think 3 months can be too soon to see changes . . . I was born with a profound hearing loss so it took a longer time to benefit.

Lifelong funding for CI is a major issue which is often not considered:

- “ The ongoing cost was a surprise to me. That should be explained upfront.
- “ My insurance here in *** isn’t willing to cover aural rehab so I’m filing grievances to fight for it.
- “ 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 that is a huge on-going cost.
- “ In Europe there are countries where users are not able to cover the costs of repairs.
- “ The money is not always invested in the best way. That’s a problem . . .

Managing the technology is challenging; industry has a role to support users in this and ensuring the technology is user friendly:

- “ 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 . . .
- “ CIs come with a box of technology -- even the brightest people don’t know what to do with the assistive tech in the box . . . they think we are all IT specialists!
- “ We needed much more patient/user input to the design and tech process in the development of the tech.
- “ Some of the assistive technology is so hard to use that I’m still struggling with it as a user after 8 years.
- “ This is where industry can help.

Appointments should respond to user need and be individualised:

- “ When I tried to convey my concern about waiting an additional year to be 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. I should just keep practicing and doing what I had been doing. It became clear to me that I was going to need to do a better job of self-advocacy.
- “ 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 feel a lot of pressure that I would be bothering them if I contact them. They ask us to come back in a year’s time, but don’t check to assess us if we are satisfied, maybe in a month or 6 months. it’s always after one year. Sometimes we feel we have lack of confidence to reach out if we want some changes.
- “ We don’t have a pathway for young CI users as they become adults and transition from being cared for by their parents, to when they become adults and have to start looking after themselves.
- “ Adverse events follow up by clinics must be addressed in a timely and appropriate manner . . . I am not sure they are getting their issues addressed or investigated thoroughly.

