The Living Guidelines Project: CIICA Conversations

Context

The Living Guidelines project aims to address the significant under provision of CI for Adults and improve outcomes for adults with hearing loss. The project has created global living practice guidelines to optimise the standard of care for eligible adults, based on the best existing research evidence of what works.

CIICA held four CIICA Conversations on the project, to involve users and families, providing opportunities to comment on the questions and its recommendations. The CIICA Conversations were chaired by Leo De Raeve, Chair of CIICA, and a lead on the project, and were facilitated by users and families. CIICA Conversations are one hour long, with a maximum of 20 participants, are not recorded and are live captioned. Following each Conversation, a summary of the issues which arose was made, and circulated for agreement. This report summarizes those individual summaries and the issues important to the users and their families.

Key points to emerge from the four conversations:

- 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.
- There needs to be greater awareness of the impact of HL (hearing loss) and of CI:
  the CI should be part of the lifelong hearing journey: the transition from HA to CI is much greater than recognised
- Lifelong funding for CI is a major issue which is often not considered
- **Person and Family Centered CI services** are vital for the best outcomes in real life, and the family and significant others should be involved in partnership with professionals
    - 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
    - Regular programming and rehabilitation are key to progress: appointments should respond to user need and be individualised
    - Rehabilitation should include a counselling role: coaching can be key
    - Peer groups have major role to play before and after CI; they need guidelines
    - Managing the technology is challenging; industry has a role to support users in this and ensuring the technology is user friendly
    - Outcomes important to researchers and users can differ: Quality of life outcomes, including changes in confidence are most important to users and families
    - Assessments and their purpose should be clear and understandable to users and families and reflect functioning
    - Assessments should have a longer time frame and reflect diversity of users
- 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.

The themes from the analysis of the Conversations :

1. The need for Living Guidelines:

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.*

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.

The discussions highlighted 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.

> *for the systems everywhere standardization would be helpful for everyone….I know it's difficult when you factor in different policies.*
>
> *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.*
>
> *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.*

2. Increasing awareness of the impact of Hearing Loss and of CI:

There was a consensus of opinion that the Guidelines offer an exciting opportunity to address the lack of awareness of HL and CI not only in society but among professionals, including audiologists, to encourage timely referral:

> *Basic guidance must be provided for CI users and audiologists need to understand daily living with hearing loss.*
>
> *Audiogram and free-field is not an accurate or representative picture of how a person with hearing loss manages daily in their environment.*

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:

> *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.*
>
> *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.*
>
> *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.*

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.*
>
> *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?*

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.

> *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.*
>
> *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 the UK, the British Cochlear Implant Group works with the British Academy of Audiology to provide referral guidelines; see www.bcig.org.uk

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.*

3. CI as Part of the Hearing Journey: a "big step"

> *We are all on a 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. The term "hearing journey" was used frequently – with CI being considered as part of the hearing journey – and one which should be considered as an option earlier than is usually the case, so the person with hearing loss can consider the big step that it represents. The transition from hearing aid to CI was considered huge, largely because of surgery and ongoing commitment. There were many comments about the length of time individuals had taken to make the decision to have a CI, with many regretting that they hadn't had it earlier.

> *I have found when I am talking to people who are going through the CI journey it's 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..*

Clearer information could promote earlier access:

> *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 till 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.*
>
> *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.*

4. 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 it's 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.*

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*
>
> *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.*

5. Person and Family Centered Services

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.

> *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.*

However, it was agreed 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.*
>
> *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 such an 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.*

With regard to the Living Guidelines, the challenges of using them in a person-centred approach was considered:

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

5.1 Accessible information "Democratising" information

A term came up and was shared – "**democratising the information"** which summed up the conversation about accessibility and providing information to be used for informed decision making.

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

For some, factual information about expected levels of hearing was key to decision making:

> *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.*

5.2 Lifelong Rehabilitation Services: what should they include as part of Person and Family Centred Services ?

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.*

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. There needs to be the recognition of lifelong services:

> *I think you have to strongly emphasise that the patient is life long, it can be a 100 year process (where an infant implanted)*
>
> *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.*

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 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. 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. For some, music was important: *finally, to be able to enjoy it with the cochlear implant – that was success.*

Also mentioned was the range of patients' rehabilitation needs, arguing 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.

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).

> *I hear from some people that they never see their surgeon again and there's no clear path of rehabilitation. 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*
>
> *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 (should be included)*
>
> 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.
>
> *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.*

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.*
>
> *It (the guidelines) 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.*

Expectations were considered important:

> *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.*

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. It's been a week now, and it's been a lot quieter, but 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.*
>
> *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.*

5.3 Including Technology management in Rehabilitation

CI involves the daily use and maintenance of technology. 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 and ongoing 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.*

There was frequent mention of the challenges of learning how to manage this complex technology, and how partnership with industry can help with this:

> *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.*
>
> *Industry can help with this...*

There were particular issues with new accessories and programmes; and becoming familiar with their managing Support for this need not be done by highly qualified audiologists, and peer groups can have a role in developing confidence.

> *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.*

5.4 Psycho social input/ Counselling

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 that is not often addressed and this became a major talking point. 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.*
>
> *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.*
>
> *psychological help is necessary for some clients and should be implemented as part of the assessment.*

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.

> *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.*
>
> *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.*

5.5 Peer to peer support

For many, meeting others had been key to proceeding with the decision for implantation. The issue of peer-to-peer support was one that was referred to frequently and considered important to be included in some way, both before and after implantation. 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.

> *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..?*

Several people mentioned the importance of meeting others during assessment and decision making: 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 (those in assessment) 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 disappoint.*
>
> *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.*

Some 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.*
>
> *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.*
>
> *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 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.***

Family support

The groups also need to include significant others and family members; not 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.*

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.*

Peer groups were considered important at all ages; the Conversations 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:

> *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...*
>
> *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 processors 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.*

6. Assessment of progress: What outcomes are important to users and families?

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 making decisions, and to monitor progress to inform rehabilitation and mapping programmes. To achieve this, outcomes were needed to be accessible and understandable to user and their families, but also to funders and public health decision-makers.

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

There was frustration expressed that often the reasons for the assessments were not explained to the CI user, and the assessments did not reflect reality. There can be a discrepancy between clinic scores and what is happening in everyday life and there was also frustration about how testing was done. A comment from an audiologist and CI user:

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

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.*

There was also discussion about who needs the test? Assessment results can be used for disability benefits or for funding purposes – to provide tests done in ideal conditions does not give an accurate reflection of everyday functioning.

> *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.*

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

> *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.*

> *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.*

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

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 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.*
>
> *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. It's not just about what we hear but the cognitive listening effort and recognition.*

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.*

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….*

Measuring Quality of life changes

The topic of quality of life and its measurement was a focus of the Conversations. A definition of global quality of life was given:

> *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.*

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)

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

> *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.*
>
> *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.*
>
> *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.

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. Given the impact of CI on the whole family:

> *Maybe an outcome measure for the effect on the family/significant other?*
>
> *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. My mother is a good user, but she 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, and I can even go to the movies with my Mom.*
>
> *If I were to choose one thing, it's 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.*

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.*

7. Using the Guidelines

Participants in the Conversations were enthusiastic about the potential of the Guidelines to improve CI services and were focused on how they could use the guidelines to improve awareness, access, and provision. They were keen to support their implementation. 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.*
>
> *Users can participate mainly by spreading positive experiences, practical advice, explanations of what it's like to live with CI.*

If there is little awareness about CI referral 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. They discussed the resources which would be helpful for user and family groups to utilise to share the Guidelines.

> *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.*
>
> *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*

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…*

Some challenges were considered: comments about the sustainability of the guidelines: *"how can we ensure the guidelines are sustainable and kept up to date?"*

The group really valued these Conversations: *it is a marvelous opportunity.*

> *I'm sorry I'm not too smart at the technology but glad I was there tonight!*

CIICA.AISBL March 2023

For further information go to:

> LIVING GUIDELINES FOR CI FOR ADULTS – CIICA (ciicanet.org)

Go to Living Guidelines | Adult Hearing to download the draft recommendations which are open for consultation until 31 May 2023.