

CIICA Conversation: Experiences of Tinnitus and Cochlear Implants

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Facilitators: Robert Mandara, Finland, Maggie Whittemore, USA, Kelly Assouly, Belgium

Observer: Sue Archbold, CIICA

Participants: 7 users of CI; 1 Researcher, 1 Rehabilitation specialist, 2 Advocacy leaders, Live captioning was provided. CIICA Conversations last for one hour and are not recorded. Participants were from 8 countries: Belgium, Canada, Finland, Germany, Ireland, Kyrgyzstan, Slovenia, UK, and USA.

Introductions:













Robert Mandara. Vice-President, EURO-CIU, Bilateral CI user and tinnitus sufferer
Maggie Whittemore, late onset deafened, CI user and tinnitus sufferer.
Kelly Assouly, Researcher on the effect of CI on tinnitus - at UMC Utrecht (NL) and Cochlear (BE).
Attendees also introduced themselves via the chat room and beforehand.

Framing the Conversation

Robert introduced the possible issues to address, emphasising that we were discussing tinnitus AND CI

- Did you discuss possible tinnitus changes with your audiologist before implantation?
- Has your tinnitus changed in either ear since CI? How about at night?
- If applicable, do you have any hunches for why your tinnitus changed?
- How does your tinnitus affect your hearing and daily life?
- What suggestions do you have for tinnitus researchers?

In introducing the title of Tinnitus Trajectories, Robert used the following diagram, and asked people if they were Tom, Dick or Harry, etc.

	Before CI	Before activation	Since activation (CI on)
Tom	-	-	-
Dick	-	-	
Harry	-		-
Anne	-		
Sarah		-	-
Mike		-	
Linda			-
Bob			

This provoked some discussion. There were several “Bobs” and one lucky “Linda”!

Summary of the verbatim live discussion and chat room comments:

Following the discussion of the concept of trajectories, there was the discussion of tinnitus experiences before implantation. One had experienced tinnitus from childhood, while several had experienced increasing tinnitus as their hearing loss progressed. Discussions about tinnitus before implantation had been careful about raising expectations:

Hope but no expectation that my tinnitus would change

We don't set any expectation on tinnitus changes

Tinnitus had often been the deciding factor in going for a CI:

I got my cochlear implant for tinnitus relief.

In my case tinnitus was the deciding factor in having an implant.

However, this was difficult if the clinician didn't discuss this, assess the tinnitus or was able to advise:

I think it can be a bit scary when you don't know what will happen, that was one of the big points in this discussion.

To be told you have to ignore it is really hard.

I think we should work more to make sure that counselling is available and there is support.

The discussions before CI ranged from the not helpful:

He did not take me seriously

We cannot help you

I do not recall my doctors brought up tinnitus at all and it was a very real concern of mine because it was driving me crazy and was constant all the time.

To the extremely helpful, which included full assessment of the tinnitus experience.

The full assessment was carried out in the case of sudden onset Single sided deafness:

My single sided deafness was trigger to severe tinnitus.....it was every waking hour and reacted to the environment I was in. Upon activation the tinnitus just went,it's there but in terms of quality and volume it's pretty much gone. ...I go swimming and I take it off and I have loud tinnitus under water, or go to bed and it comes back in 30 seconds. I put back my CI to get some more sleep. ... Would it eventually go away if you continuously had auditory experiences and your brain was not making stuff up at night?

One of the most useful things in the whole process was the audiologist actually assessing my tinnitus.her eyes were widening as she cranked up the volume... it was the first time that somebody acknowledged that you are not imagining it.

The assessment of tinnitus – in quality and quantity – was a rare experience and one which was strongly felt should be explored further by research. Tinnitus was considered to be grouped together and this was not helpful, nor likely to find any solutions or understanding of the issues.

I think it's a really useful exercise to do to actually simulate the sound so that other people can understand.

I have not been aware that kind of assessment might be available for my situation.

Different types of trajectories:

- Suppressed after activation
 - *Upon activation the tinnitus just went,it's there but in terms of quality and volume it's pretty much gone.*
- Much better, less loud sound when CI on
 - *When I put my implants down I can hear different sounds ...but yes it is much better*
 - *Much better after implantation*
 - *It was much worse with hearing aids.*
- Changed the nature of the sound
 - *I am happy with my implants, but I also have tinnitus when I put my cochlear implants down, then I have other music in my head.*
 - *The only thing I can say is that my tinnitus has changed. It's not as intrusive but it's as loud, it's always there. I don't have the clicky sound anymore and it's great to be rid of it.*
 - *The nature of my tinnitus has changed. It's more complex right now., it's multi-layered, it's almost a bit of a symphony going on. ... After my second implant I had a much more generalized tinnitus, almost like a roaring sound. ... All the pinging and popping and triangle players are still there. =*
- No change
 - *In my case it did not (change) I still have a shrill symphony all of the time... it does impact on my day very much, my cognitive energy, my ability to focus.*
- A consensus that over-stimulation and fatigue exacerbate tinnitus.
 - *To this notion of over-stimulation, I would add fatigue. ... I am fighting with the tinnitus to be able to determine to be able to understand, to be able to hear*

Impact of electrical stimulation

How does mapping impact tinnitus? There were a few examples given where mapping was considered to impact on tinnitus and over-stimulation to be related to worsening or even creation of, tinnitus.

I am lucky I have only experienced tinnitus a few times...I had it before my implant when I was in bed, but not so often since my implant. A few weeks after activation it happened and it seems to be due to over-stimulation. After reprogramming it was gone in a day or two.

I don't know if I am over-stimulated or under-stimulated!

One participant had experienced tinnitus after being in a loud situation for several hours.

I find this conversation about the degree of stimulation interesting. I dialled back on the volume and programme I was listening at. I also feel that you can over-stimulate... but you always need a certain amount of volume to keep it at bay.

The other view was also explored – if there is not enough stimulation is there a problem that the tinnitus will not change?

Experimenting with mapping could be a good research project.

Challenges caused by tinnitus with CI in the clinic

I think that that doctors do not take so seriously tinnitus which we have – for me in the past it was very hard to sort out the tinnitus from listening sounds in the audiogram.

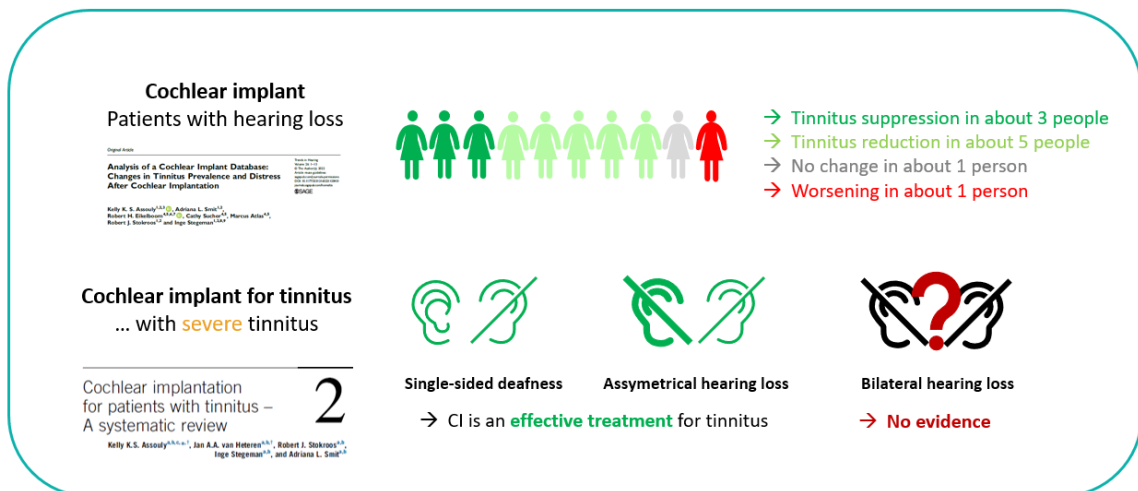
What do you think that tinnitus research should focus on now?

- Subtyping tinnitus groups depending on the type of tinnitus
 - *I have never seen researchers trying to split us up in terms of our tinnitus (there's a quite finite number of different types of tinnitus sounds, whistling, clicking etc.)*
- Prospective assessment with brain imaging to understand the mechanisms of action (CI on/CI off)
- Would tinnitus go away if I use electrical stimulation throughout the night?
- Why is tinnitus improving for some patients and not for others?
- Is there difference between busy (e.g. working) people and relaxed (e.g. retired) people in managing their tinnitus?

What is the impact of mapping/electrical stimulation on tinnitus?

Comments and information from Kelly Assouly

Tinnitus changes in literature



→ Depends on the hearing loss profiles and other factors
→ No good prediction model for tinnitus changes currently



Kelly presented an overview of the tinnitus changes observed in the literature after cochlear implantation. For this purpose, she used two studies as a support for discussion:

1. In a cohort of 300 people with severe to profound hearing loss, different changes in tinnitus distress were observed after implantation:
 - 3 / 10 experienced a total tinnitus suppression
 - 5 / 10 experienced a reduction in tinnitus distress
 - 1 / 10 experienced no change in tinnitus distress
 - 1 / 10 experienced a worsening in tinnitus distress

These proportions are relevant with what has been observed in other studies on the topic. Currently, we still cannot understand and predict these changes among cochlear implant candidates. Further research with big data is needed to progress on the prediction of tinnitus changes after cochlear implantation.

Reference: Assouly KKS, Smit AL, Eikelboom RH, Sucher C, Atlas M, Stokroos RJ, Stegeman I. Analysis of a Cochlear Implant Database: Changes in Tinnitus Prevalence and Distress After Cochlear Implantation. *Trends Hear.* 2022 Jan-Dec;26:23312165221128431. doi: 10.1177/23312165221128431

2. An overview of the literature showed that for people suffering from severe tinnitus before implantation:
 - For people with single-sided deafness or asymmetrical hearing loss, cochlear implant showed an overall positive effect on tinnitus.
 - For people with bilateral hearing loss, there is not enough evidence to say something on the effect of cochlear implant on tinnitus.

Reference: Assouly KKS, van Heteren JAA, Stokroos RJ, Stegeman I, Smit AL. Cochlear implantation for patients with tinnitus - A systematic review. *Prog Brain Res.* 2021;260:27-50. doi: 10.1016/bs.pbr.2020.06.013.

Summary

There was a lot of discussion in this Conversation with a combination of the lived experience with reflection, and with a lot of research and evidence information shared. People valued being able to share their experiences:

A lot of what people said resonates with me. I documented my experience of the process on a blog which is available at noisysilence.ie

The tinnitus post is here: <https://noisysilence.ie/2023/02/03/tinnitus-talk/> It is an evolving process which will hopefully be updated over time.

A lot of what has been said resonates to me and my experience.

A lot of people have explored this area in detail and we plan to have a research round up on tinnitus in the Community Members area. It would be good to share what has already been done, while thinking about what next!

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