

## **CIICA Conversation: CI AND TINNITUS: WHAT DO WE KNOW AND WHAT DO WE WANT TO KNOW?**

**29 September 2026**

**Facilitators:** Robert Mandara, CI User, Finland; Kelly Assouly, Researcher, France; Charlotte Young CI user, UK

**Observer:** Sue Archbold, CIICA

21 Participants include 10 or more users of CI, CI candidates, Hearing aid users, CI specialists, Researchers, advocacy leaders, industry, people with tinnitus.

Live captioning was provided. CIICA Conversations last for one hour and are not recorded.

Participants were from 12 countries: Canada, Spain, Denmark, Hungary, Finland, France, India, Ireland, India, UK, USA, Wales.

### **Introductions:**

Robert Mandara. Bilateral CI user and tinnitus sufferer

Kelly Assouly, Researcher on the effect of CI on tinnitus - at UMC Utrecht (NL) and Cochlear (BE).

Charlotte Young, tinnitus sufferer, CI user and Advocate

Attendees also introduced themselves via the chat room and beforehand.

### **Framing the Conversation**

The conversation aims to discuss the different journeys of tinnitus and cochlear implants. It's not just about tinnitus; it's related to the cochlear implant journey.

Robert introduced the conversation by inviting participants to ask questions about tinnitus and CI. He suggested a few examples questions:

- Are there any objective measures of tinnitus?
- Can we predict which CI candidates will have the best/worst tinnitus outcomes?
- Are there correlations between tinnitus and other health issues/(mis)diagnoses?
- Does the intensity of tinnitus follow any biological rhythms?
- Would wearing our processors and hearing 24/7 reduce tinnitus suffering?
- How many kids with CI have tinnitus? Who is asking them and how?

### **Summary of the verbatim live discussion and chat room comments:**

Kelly Assouly presented two research studies: one assessing the effect of tinnitus on CI programming and another one assessing the effect of CI programming on tinnitus. Her PP is attached as a PDF. Please find below a summary of the two studies presented:

## Effects of Tinnitus on Cochlear Implant Programming

Trends in Hearing  
Volume 23: 1–15  
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DOI: 10.1177/2331216519836624  
journals.sagepub.com/home/ta  
SAGE

Robert H. Pierzycki<sup>1,2</sup> , Charlotte Corner<sup>1,2</sup>, Claire A. Fielden<sup>1,3</sup>,  
and Pádraig T. Kitterick<sup>1,2,3</sup> 

This study has three research objectives:

1. Explore and characterize the effect of tinnitus on CI programming using interviews with experienced audiologists working across 2 large CI clinics.
2. Assess the prevalence and impact of those effects using cross-sectional surveys of adult CI recipients and audiologists.
3. Investigate the specific hypothesis that CI programming parameters obtained during clinical appointments differ in patients with tinnitus from those without tinnitus.

The survey was completed by 67 adult CI patients with tinnitus and 20 CI audiologists in the United Kingdom. Please find below interesting outcomes resulting from the analysis of the survey:

- **84%** of patients reported that the onset of their tinnitus occurred before CI surgery  
**5%** of patients reported that tinnitus started after implantation but before implant activation  
**11%** of patients reported to have developed tinnitus after CI activation.
- Patients and audiologists reported that tinnitus makes programming appointments more difficult and tiresome for patients.
- **80%** of audiologists and **45%** of patients reported that tinnitus makes measurements of threshold (T) levels more difficult because patients confuse their tinnitus with CI stimulation
- **26%** of patients reported being afraid of “loud” CI stimulation worsening tinnitus, affecting measurements of loudest comfortable (C) stimulation levels
- When comparing T and C levels of CI recipients with and without tinnitus, they found that T levels were significantly higher on average by 1.7 dB in patients with tinnitus than in those without ( $p = 0.048$ ).



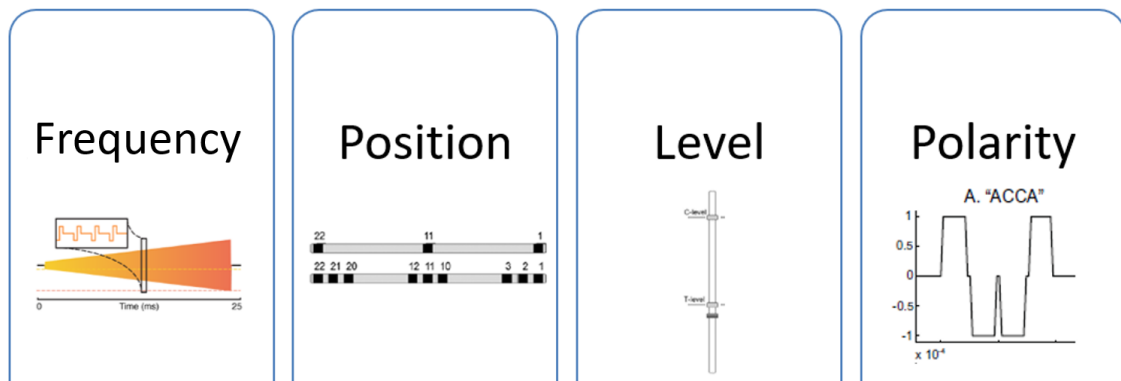
Review

## Systematic Review on Intra- and Extracochlear Electrical Stimulation for Tinnitus

Kelly K. S. Assouly<sup>1,2,3,\*</sup>, Max J. Dullaart<sup>1</sup>, Robert J. Stokroos<sup>1,2</sup>, Bas van Dijk<sup>3</sup>, Inge Stegeman<sup>1,2</sup>  
and Adriana L. Smit<sup>1,2</sup>

This study systematically reviewed the literature on the effect of CI programming as a treatment option for tinnitus. A total of 10 studies (89 patients) investigated the effect of CI programming on tinnitus. Several parameters such as frequency rate, position of the electrode, current level and polarity were tested (see illustration below). Studies evaluating the effect of electrode position have suggested that stimulation of all electrodes is more effective than activation of only a few basal, apical, or pitch matched electrodes. Due to methodological limitations and the poor quality of the

reports from the included studies, the potential of CI programming has not been fully explored. One hypothesis is that the optimization of parameters appears to depend on each individual patient.



Charlotte Young presented her cochlear implant journey and shared her tinnitus experience and her reflections. See some of her slides below:

## Why Every Journey Sounds Different

| Situation         | My tinnitus experience                                      |
|-------------------|-------------------------------------------------------------|
| Before CI         | Hissing, fizzling sound                                     |
| Processor ON      | Tinnitus feels like it has switched off                     |
| Processor OFF     | Overwhelming hissing and fizzling initially then it reduces |
| Tired or stressed | Tinnitus is more prominent                                  |
| When ill          | Heightened                                                  |



## CI and Tinnitus



### Reflections as a CI user....

Tinnitus can change post CI and at different stages

Discussion around this during the assessment process

Ways to access support and guidance

Not to listen or trust quick fixes you see online

## Questions....

What should you do as a

CI user if your tinnitus

worsens?

Do CI centres have a

tinnitus specialist?

Is there appropriate awareness

and guidance from audiology

teams to support candidates

and users with tinnitus

currently?

Can tinnitus change with

different programmes &

after tuning

appointments?

There followed an open discussion on different tinnitus journeys:

### Tinnitus awareness

- Several recipients shared his story about having tinnitus since childhood.
- Several recipients have been aware of having tinnitus often mentioned later in their hearing journey.

*"I have had tinnitus all my life. In fact when I was a kid I thought it was just a normal thing. I thought everyone had sound in their head all the time. And as I got older and understood a little bit more, started to realise this is not a normal situation and mine actually progressed from like crickets, and the high pitch ringing to about three or four years before I lost all of my hearing to just a really loud jet engine roar. So that is what I have lived with for probably the past ten-plus years."*

- How difficult it is to convey how your tinnitus is. Art can be a way to represent tinnitus and share your experience with others.

### Tinnitus change

*"I remember going into surgery and having a moment of panic, thinking, what if this actually takes away my tinnitus and for the first time in my life I am exposed to actual silence? Like, what is that going to be like?"*

### Tinnitus gets better...

- When wearing the processor, tinnitus is reduced in several recipients. It is a switch/turn on for some recipients, where tinnitus disappears.

*"On activation day I could hear things again. Voice recognition after this activation and the tinnitus, I just couldn't hear it. I heard silence that day of the activation. It is still there when I take the implant off. It is there at night. I think it has diminished compared to the past when I take the implant off."*

- One recipient changed his diet and he noticed that his processor programs became too loud, he changed his CI programs and his tinnitus reduced.

*"I would change what I was eating and I cut out sugar and caffeine. I don't drink alcohol, anything that could ramp up inflammation. I was cutting it out of my diet. I didn't notice it right away but about six months after that I did that, my tinnitus started to quieten down and I asked my audiologist about it. Not only had my tinnitus quietened down but my processors became too loud like it was easier for me to hear and I started, we started pooling all the perimeters down on my thresholds dropped steadily over a year until they finally stabilised again. So, now I have better maps, less tinnitus, and my tinnitus is as quiet as it's been in decades right now."*

- One recipient had a mind shift and learned to live with her tinnitus. Since then, tinnitus is less bothersome.

*"I have been following a Keto diet for probably about three to four years now. One thing I have not cut out is caffeine. So perhaps maybe that might be something that I could work on. [...] I myself didn't personally notice as much of a change in the tinnitus levels after being keto. But I think the thing that helped me the most was a mind shift change."*

#### Tinnitus gets worse...

- Tinnitus got a little worse after surgery for some.
- When not wearing the processor, tinnitus is becoming louder. This is problematic at night.
- Tinnitus is louder when stressed and sick.

#### Effect of tinnitus on cochlear programming

- T levels are hard to hear as it interferes with tinnitus.
- The audiologist helps by creating multiple beeps/stimulus to help to recognize if it is tinnitus or several beep.
- Listening breaks can help.

*"I think there is so much we can do in programming around perhaps using different tones or making sure that we have listening breaks or making sure we have sensory tools in the room which can support people to get the most from their programming appointments"*

#### Hearing 24/7

- Total Implantable or fully implantable CIs are being researched- would be interesting to have "CI" hearing all the time and how that would help with tinnitus.
- Some people would like to hear 24/7, some love being able to "unplug" every night.
- Could it be a potential to reduce tinnitus while sleeping?

*"I honestly prefer not hearing anything but the tinnitus"*

*"I would love to hear 24/7!"*

Thanks to all who joined us and Charlotte and Robert.

Kelly Assouly, September 2026.