

## CIICA Conversation: What Does a 5 Star Adult CI Service Look Like?

**8 September 2026**

Facilitators: Kris English, Prof Audiology, USA

Michelle Frisbie: Bilateral Implants; board member of Hearing Loss Assn. of America (HLAA) as well state & local chapters, Wisconsin USA; Paul Sommer, CI user, Sr Director, Pt Advocacy, Regeneron, Certified Pt Experience Professional (Beryl Institute), Certified Professional Pt Advocate, PPALS, Pennsylvania USA.

21 Attendees from 8 countries: 11 users of CI; with audiologists and therapists. Live captioning was provided. Participants were from Belgium, Canada, Denmark, Paraguay, Pakistan, Spain, UK and USA.

This summary is prepared from the transcript, the comments in the chat room, with input from ChatGPT.

### **Introductions:**

Kris welcomed everyone, provided some housekeeping notes, and encouraged attendees to introduce themselves via the chat room. She reminded everyone that the meeting was not recorded but a summary, based on the transcript, would be shared and would contain anonymised quotes.

### **Framing the Conversation: Meeting Purpose**

Kris explained some of the background to this Conversation from previous ones, with the purpose to explore what "5-star" care means within cochlear implant (CI) services, examine current barriers to quality care, and gather input from users, advocates, and professionals on establishing service quality benchmarks.

She reminded the group of the **Origin of the Topic**: Prompted by advocate Robert Mandara's suggestion to create a "TripAdvisor-style" rating system for CI services to address widespread dissatisfaction and track service standards and considered the context about **Defining "5-Star" Care**: focussing on whether current care is truly personalized, flexible, and supportive of the individual, and culture free, rather than rigid and schedule-driven.

**Michelle Frisbie** (note: not speaking on behalf of any organization) shared her background:

**Personal Journey**: Bilaterally implanted; received her first implant 25 years ago via an unexpected cancellation slot, and her second implant 10 years ago after navigating insurance coverage challenges across different clinics.

### **Her personal 5-Star Priorities:**

- *Patient-Centered Care*: Continuous care across the lifespan.
- *Insurance Navigation*: Active administrative support for coverage approvals.
- *Peer Support*: Access to implantee references, mentors, and local support groups.
- *Comprehensive Information*: Full transparency and training regarding device options, apps, and accessories.
- *Rehabilitation*: Access to funded, in-person aural rehabilitation (moving beyond self-directed apps or audiobooks).

She commented: *"Patient-centered care across the whole continuum, from diagnosis until we're no longer here... I think other people should be helping us navigate [insurance]. I did not have a very good experience with that."*

She also considered that CI users should be participating in decisions about their care and the use of their CI, including programming.

*"So many people I have spoken to have felt rushed and not listened to."*

*"It makes me frustrated... the fact that these things [device settings and features] have to be activated by the audiologist before they can be seen and available to an implantee."*

Another participant commented: *I've always wanted even more input and control though, especially when they make tweaks and then if I don't like it, I have to wait until another appointment which is frustrating...."*

And another: *I wouldn't have received the open programme for music if I hadn't been advised to ask for it by peers."*

**Paul Sommer** (note: not speaking on behalf of any organization including his employer) then shared his background:

**Personal & Family Experience:** Born deaf, received CIs at ages 28 and 33. He highlighted the contrast between his smooth, coordinated team-based care and his wife's (Sarah's) disjointed, stressful experience at a different facility.

- Paul discussed Patient Satisfaction Surveys: Noting that standard US healthcare surveys often measure logistical convenience (e.g., parking, waiting rooms) rather than the depth of personal, respectful care.
- He shared a measure of satisfaction of health care from a sample PressGaney.com survey:

| CARE PROVIDER                                                                                    | very |   | poor | poor | fair | good | good | very |
|--------------------------------------------------------------------------------------------------|------|---|------|------|------|------|------|------|
|                                                                                                  | 1    | 2 | 3    | 4    | 5    | 6    | 7    | 8    |
| <b>PLEASE ANSWER THE FOLLOWING QUESTIONS WITH THAT HEALTH CARE PROVIDER IN MIND.</b>             |      |   |      |      |      |      |      |      |
| 1. Concern the care provider showed for your questions or worries.....                           | 0    | 0 | 0    | 0    | 0    | 0    | 0    | 0    |
| 2. Explanations the care provider gave you about your problem or condition.....                  | 0    | 0 | 0    | 0    | 0    | 0    | 0    | 0    |
| 3. Care provider's efforts to include you in decisions about your care.....                      | 0    | 0 | 0    | 0    | 0    | 0    | 0    | 0    |
| 4. Care provider's discussion of any proposed treatment<br>(options, risks, benefits, etc.)..... | 0    | 0 | 0    | 0    | 0    | 0    | 0    | 0    |
| 5. Likelihood of your recommending this care provider to others.....                             | 0    | 0 | 0    | 0    | 0    | 0    | 0    | 0    |

And illustrated it with the differing responses from him (green box) and Sarah (red box):

| CARE PROVIDER                                                                                 | very |      |      |      |      |
|-----------------------------------------------------------------------------------------------|------|------|------|------|------|
|                                                                                               | poor | poor | fair | good | good |
|                                                                                               | 1    | 2    | 3    | 4    | 5    |
| <b>PLEASE ANSWER THE FOLLOWING QUESTIONS WITH THAT HEALTH CARE PROVIDER IN MIND.</b>          |      |      |      |      |      |
| 1. Concern the care provider showed for your questions or worries.....                        | 0    | 0    | 0    | 0    | 0    |
| 2. Explanations the care provider gave you about your problem or condition.....               | 0    | 0    | 0    | 0    | 0    |
| 3. Care provider's efforts to include you in decisions about your care.....                   | 0    | 0    | 0    | 0    | 0    |
| 4. Care provider's discussion of any proposed treatment (options, risks, benefits, etc.)..... | 0    | 0    | 0    | 0    | 0    |
| 5. Likelihood of your recommending this care provider to others.....                          | 0    | 0    | 0    | 0    | 0    |

Paul summarised his message: *"Simply put, the better the experience is, the more engaged patients and families are, and therefore the better outcomes are."*

### He suggested 3 Strategic Moves for 5-Star Experience and "Bridge the Care" Gap

1. **Care Coordinators:** Dedicated points of contact to assist throughout the journey to manage appointments, set expectations, and provide a continuous point of contact.
2. **Peer Mentorship:** Formalized networks to support the complex process, to help candidates navigate choices and information without sales bias, and to know what to ask for during appointments.
3. **Service-Level Standards:** Reliable access and reasonable travel/scheduling parameters for ongoing mapping and programming. For example, Paul had 4-5 appointments back to back when he went for his initial CI appointment with the cochlear implant center coordinator, audiologist, surgeon, psychologist, etc. On other hand, Sarah met with the surgeon up front but was told she would have to call to make separate appointments with all the same aforementioned people and hope she could get them all the same day. Paul was also offered the option of any of the three CI brands whereas Sarah had no choice but to go with just one brand because despite being a leading medical center – they only had contract with that one company.

The discussion that followed highlighted several participants with experience of what they considered to be 5-star service:

One participant highlighted his high-performing and well-starred center offering high-volume surgeries, 5 regional telemedicine sites, CT-guided post-op mapping, full access to all three CI brands, annual community picnics, pediatric camps, and dedicated auditory-verbal therapy. *I feel very lucky.*

Where challenges were experienced, these issues were mentioned:

**Staffing Shortages:** Participants noted severe audiologist shortages leading to cancelled annual check-ups, delayed mappings, and unmanaged care plans (e.g., waiting over six months for a one-year follow-up).

- *"My one-year was scheduled for April then they cancelled it... my audiologist moved out of area... it's been like another 6 months, I have not had my one-year follow-up or mapping... I am basically doing my own rehabilitation."*

Lack of aural rehabilitation was mentioned too:

- *"When I had my first one, they said – 'here you are, you're implanted, go hear.' Now there are much better resources."*

**Travel Burden:** Patients frequently travel up to 5 hours round-trip for appointments, emphasizing the critical need for remote tuning, remote troubleshooting, and telehealth options.

- *"My centre is a 5-hour journey round trip for me. I think with technology now it's great that check-ins can be done remotely... you need to be able to troubleshoot things quickly when you have these anxious moments."*

**Mental Health:** Strong call for integrating anxiety, grief, and adjustment counseling into routine CI care.

- *"One thing they haven't done much of and are expanding—and I think every centre ought to have—is psychological support, because it's those patients with anxiety... it's extremely difficult to get them through the door."*

**Family Education:** Emphasized that hearing loss impacts the whole family. UK initiatives were mentioned providing comprehensive informational booklets to set expectations and guide relatives on how to support the user.

#### **Summarising the discussion:**

#### **Gaps in Current Services:**

A global shortage of audiologists leading to long delays/cancellations, lack of mental health/psychological support, geographical barriers requiring long travel times, and inconsistent post-implantation follow-up

#### **Key Components of 5-Star Care were summarised:**

- **Lifelong Patient-Centered Care:** Continuous support spanning initial diagnosis through long-term maintenance.
- **Insurance/Funding Navigation Assistance:** Active, dedicated support from clinics to secure insurance coverage and approval of funding.
- **Peer References & Support:** Direct referrals to peer mentors, support groups, and existing CI users before and after implantation.
- **Comprehensive Device Education:** Full transparency and technical instruction regarding all available device options, accessories, and smartphone applications.
- **In-Person Aural Rehabilitation:** Moving beyond self-guided audiobooks or apps to offer fully funded, clinic-based auditory training.
- **Responsive Customer Service:** Timely communication from both manufacturers and clinical staff for non-emergency inquiries.

#### **Based on their experiences, Key Action Items & Recommendations for CI Centers:**

- **Ensure Competency in Advanced Features:** Audiologists must actively and train patients about program device features (e.g., sensitivity settings, forward focus, accessories) to achieve optimal outcomes.

- **Expand Remote Care:** Standardize remote mapping and virtual check-ins to alleviate travel burdens and address staffing bottlenecks.
- **Formalize Volunteer & Peer Training:** Provide structured training (informed by experienced CI users) for peer volunteers so guidance is consistent and effective.
- **Embed Holistic Support:** Integrate mental health resources and structured aural rehabilitation directly into the standard pathway of care.

In closing, Kris asked participants what was one thing that they would choose to mark out a 5-star service:

***"If I had to pick one thing out of everything... it would be having that super-good working relationship with a very competent audiologist. I feel very lucky."***

Participants expressed thanks for the opportunity to talk freely – and to be able to share exemplary service as well as some of the challenges.

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Kris English, Sue Archbold, Paul Sommer, Michelle Frisbie