

CIICA Conversation: Person Centred CI Services: Can we Measure them?

26 June 2024

Facilitators: Kris English (USA), Paul Sommer, USA
Observer: Sue Archbold, Coordinator, CIICA

Attendees from 7 countries: 7 users of CI; 5 audiologists, 1 teacher of the deaf, 1 speech and language therapist and a public policy specialist. Live captioning was provided. Participants were from Finland, France, India, Ireland, Netherlands, Turkey, UK and USA.

Introductions:

Facilitators: Kris is a retired professor of audiology specialising in Audiologic Counselling; Paul is a bilateral CI user who is an expert in patient engagement. Attendees also introduced themselves via the chat room.

Framing the Conversation:

Kris English began by referring to the previous conversations on the topics related to Person-Centred Care. The summaries of these conversations can be found on the CIICA resources page:

CIICA Conversations

- Adult Services After CI: Reimagining Rehab (April 2022)
- Person-Centered Care in CI services? (Feb. 2023)
- Moving on with Person-Centred Care in CI services (Sept. 2023)
- Person-Centered Care: Measuring Quality of Life (March 2024)

She introduced this inclusive model of “Aspects of the Patient Experience” from <https://www.ahrq.gov/cahps/about-cahps/patient-experience/index.html>



She then followed with

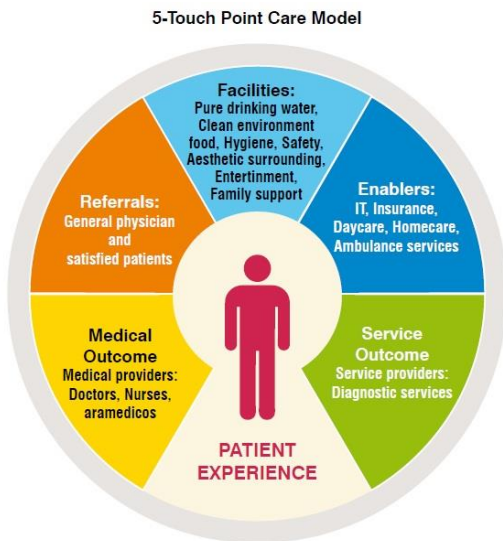
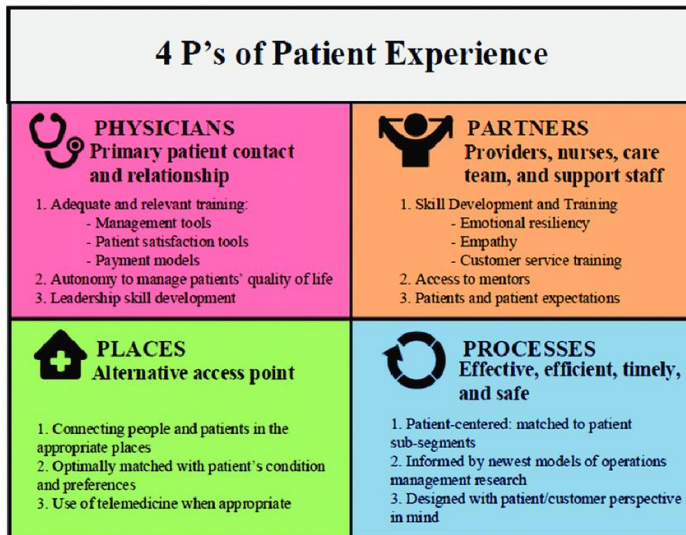


Figure 1

<https://www.asianhnm.com/facilities-operations/improving-patient-experience-safety-progression>

And this model, developed without patient input:



https://www.researchgate.net/figure/4-Ps-of-patient-experience_fig1_329689637

Kris had re-read all our conversational summaries and she commented that what was clear was that services are often not person-centred, but are driven by other priorities:

- Device/technology-centered
- Test results-centered
- Protocol-centered
- Policy-centered
- Tradition-centered
- Convenience-centered
- Clinic-centered
- Schedule-centered
- Target-centered

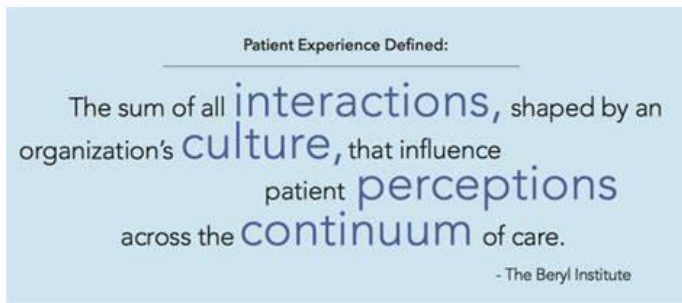
One attendee commented – and budget driven!

The better the Experience = The more ENGAGED PATIENTS/FAMILIES = THE BETTER THE OUTCOMES ARE!

Paul used this title to share the story of his CI journey and that of his wife, from the point of view of patient experience. He has been leading patient engagement programmes in health care for over 25 years and is a certified patient experience professional at the Beryl Institute (<https://theberylinstitute.org>) a US organization for people who work in patient experience in the health care setting.

What is patient experience (PX) and why is it important?

The Beryl Institute defines it as “the sum or all interactions shaped by an organisation’s culture that influence patient perceptions across the continuum of care.”



- He went on to explain that patient experience positively correlates with processes of care for both prevention and condition management. Patient experience positively correlates to processes of care for both prevention and condition management.
 - For example, diabetic patients demonstrate greater self-management skills and quality of life when they report positive interactions with their providers.
- Patients' experiences with care, particularly communication with providers, correlate with adherence to medical advice and treatment plans.
 - This is especially true among patients with chronic conditions, where a strong commitment from patients to work with their providers is essential for achieving positive results.
- Patients with better care experiences often have better health outcomes.
 - For example, studies of patients hospitalized for heart attack showed that patients with more positive reports about their experiences with care had better health outcomes a year after discharge.

Same applies for cochlear implant candidates, users, and families!!!

Reference & for more info: [Why Improve Patient Experience? | Agency for Healthcare Research and Quality \(ahrq.gov\)](https://www.ahrq.gov/patient-experience/)

Paul's story of CI journey

- Grew up profoundly deaf.
- Used hearing aids.
- At age 28 - went to a renowned CI center based on recommendations from others whom I trust. I was told I'd have a series of appointments:
 1. CI center Director – walked me through my schedule for half day
 2. Audiologist – for testing in booth and discussion re CI options
 3. CI surgeon – for exam, consultation, and Q&A
 4. Psychologist – to ensure expectations were managed
- In all:
 1. An incredibly seamless, cohesive team effort
 2. Excellent communications by all
 3. Was presented with all CI options – but would not advise which one to get! Had to do my own research and select based on my own priorities/preferences. But team happily addressed all questions I had.
- Came back for surgery. All went well and went home same day.
- And came back for follow-up mappings, which went well.

His wife’s experience

- Born hearing, but experienced moderate to severe hearing loss in one ear and profound in other ear at age 2. Wore hearing aid in better ear.
- Lost remaining hearing in other ear at age 29 just months before starting grad school
- Went to another renowned “Ear hospital” for hearing loss, but only got appointment with CI surgeon who told her:
 - Had to go here and there to schedule varying appointments here and there whenever they have a slot available.
 - She couldn’t get surgery before starting grad school
 - She could only get one CI brand – not a choice
- Called my CI surgeon to recommend another CI Center nearby. He recommended his protégé at a much lesser-known facility
- Had the best experience.

Using patient satisfaction survey:

Paul noted how he and his wife would have filled out the following survey very differently based on their various experiences!

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

Paul then commented how hospitals in the US get reimbursed based on patient satisfaction scores. He also noted that hospitals are now sharing patient satisfaction ratings and comments from their patients to not only hold clinicians accountable, but also help patients select which care provider they’d like.

Advocate for accountability!



Michael A. Burke, MD

Reviews

★★★★★ 5 of 5 stars 229 Ratings, 57 Reviews

Likelihood of recommending to others	★★★★★	5
Your confidence in care provider	★★★★★	5
Explanations about your problem/condition	★★★★★	5
Concern shown for your questions/worries	★★★★★	5
Efforts made to include you in treatment decisions	★★★★★	5
CP discuss treatments	★★★★★	5

Paul's takeaways

- Patient Experience = all perceptions and interactions across the continuum of own care
- Optimal patient experience = strong patient engagement
- Strong patient engagement = strong health outcomes, including ability to hear as well as possible with cochlear implants.
- Empower yourself and others (if and however possible) to find the right CI care providers – via word of mouth, online reviews, etc.
 - Continue to advocate for person-centered services to ensure optimal experience and outcomes
- Lastly – all of above aligns well with key takeaways from Kris, Sue, and Brian in their publication in The Hearing Journal as follows:



Cochlear Implant Users Describe Need for Lifelong Services

English, Kris PhD; Archbold, Sue PhD, Hon LLD; Lamb, Brian OBE

“It is so important that CI users have personalized and ongoing sustainable support from their professional teams to ensure that these recognized benefits (of cochlear implants) are realized.”

The attendees were the asked to complete a poll with three questions:

1. How would you describe your CI PX (briefly)?
2. Any suggestions on how to improve CI PX?
3. What kind of help might we need?

And asked to complete it about any care.

The discussion was opened up for people to share their experiences:

Patient involvement in the audiology clinic

Kris opened up the conversation about the focus of services people experience. To her list, budget focused and driven was added. The experience in the audiology clinic was discussed.

Sometimes the audiologist is not focusing on the patient they are focusing on their computer and I understand the need to do that... but in my experience, the patient doesn't get to see what the audiologist is doing on the screen. For example, I was at my hospital and I am sitting on a chair in front of the audiologist and all I hear is tap tap tap tap on the keyboard and its incessant going on ... fortunately I get on well with him, but I would have thought in a person-centred care system we would at least have a choice of being able to see what the audiologist is doing because we would then have a better understanding of the adjustments they are making , ... because all the time the audiologist is programming they are not interacting with you....

Maybe there needs to be a compromise... they need to enter what they need to do – but they could say what they are doing... eg I am going to be entering the information here for a moment... and share it..

Unfortunately the room is set up so I am on a little chair and the audiologist is on a high chair above me... it's a strange sort of power dynamic to start with.I would just like to be involved as a person and involved in what is going on..

Comments from a participant who is both audiologist and CI user:

Coming from both sides, as a client and audiologist, I do an awful lot of typing myself because I want to capture my notes, but you know my clients are sitting beside me,..... I am not talking to them when I am typing, but wait til I have finished. I've no problems about them seeing what is on the screen.....at least if they see they can see why it might be taking a long time – you're waiting for the programme to load. They ask questions, and I ask – I am doing this, is this sound better? It just keeps the interaction...

From an audiologist:

I think the best mapping allows you to share your experience with the patient - it you are not showing them what you know, then how can you engage with that? I always enjoyed to turn the screen round and sit together and talk it through. ... it needs to be tailored to people's needs ... for some people it could be a bit overwhelming...

Lack of choice

Paul had mentioned lack of choice and this was a problem for others:

There was not choice of brand I went for and I had two choices of colour – brown or beige. .. some things are budget-centred

Peer to peer involvement

One participant worked as a volunteer at her clinic, meeting up with those thinking about CI; there were sessions where people could meet others with CI and talk to staff.

I talk to people and they need someone to hold their hand, to say “yes that question occurred to me. You're not being silly” or “yes this is a genuine worry, we all have it.”

They need someone to be alongside them who has a bit of time and in so many hospitals there is one audiologist, one surgeon and one rehabilitationist. They can't interact and work together.

A fellow traveller on the way

It was felt this could be useful for parents; people get a lot of misinformation on line and talking to other parents could help:

People get distressed about what they read on line, about the choices they are making for their children. People being told that the choice they are making for their children is child abuse....these are not conversations that people bring up with the audiologist but they can have those conversations with peer support where people feel comfortable.

You don't know what you don't know: communication

The discussion continued to consider that we can't expect the person to bring up every issue – and they may not know what could be a concern. Professionals could open up conversations and make it possible for the patient to respond... eg very open questions.

Another commented on the issue of communication in the clinic; particularly if processors are switched off during testing!

If you are in the queue for CI , you are pretty inevitably going to have communication problems and challenges, so that it makes it really difficult to understand the information you are being told at the time you need it. ...

I am on the CI Facebook group and the number of misunderstandings I see and the expectations for candidates....they have got no idea about the journey.

Somebody needs to write the definitive guide for CI candidates.

Actually several have been written by user groups- we need to update and share! And we need to think about readability of information (recent ref).

Expert model clinics

There was further discussion about not being listened to about expectations and achievements:

My surgeon knew everything. He couldn't listen. ... I am a musician by profession, and he said "music is not possible, nobody can, you can't either." Then I was playing again and he said... " Ok that's your fantasy , you do not hear, you only think you hear." I know what I hear and know what I am doing. They should ask more and listen. Communication is difficult."

For several others, music was important too and important part of CI use.

The contrasting experience of Paul and his wife explained the importance of patient experience precisely. As a rehab professional— eye contact is very important to me when talking to someone.

Advocating for services and better communication and engagement

We should be a rather hard to get rid of patient....! I visit the clinic when I have to.

I see my role as a patient volunteer, as very much having to empower people and patient to take charge of their own learning, as well as being supported.

Sometimes people are intimidated by the service, and sometimes patients are intimidating!

It's definitely a two-way process: everyone has to be on side. I don't like it to be called switched on. I call it being activated: because once it's activated you need to respond to the activation. You have to play your part in getting back to hearing what you want to hear.

A good audiologist and rehabilitationist will say .. what are you hearing now? Are you hearing.....?? What would you like to hear? And discuss what can be done about it..

Paul led further discussion about assessing clinics – and the challenge of this, with the introduction of star ratings. He talked a little more about the Beryl Institute being an organisation of people in front line health care, and their training courses. You can become a certified patient experience professional. There was further discussion about the value of this, and other ways of quality assurance that exist.

[Home - The Beryl Institute](#)

“Patient Experience” rating methods were discussed, acknowledging that open-to-the-public methods tend to draw disproportionately dissatisfied reviews. Paul indicated that centers manage that problem by requesting feedback directly from known patients.

Summary

Our conversation provided the opportunity to apply an optimal “patient experience model” to actual personal experiences. Like Paul and his wife, reports ranged from very good to rather poor, and identified opportunity for change. The quality of the patient experience depends on CI centers’ awareness of/commitment to the value of patient involvement in their own care and decisions. As Paul put it:

The better the Experience = The more ENGAGED PATIENTS/FAMILIES = THE BETTER THE OUTCOMES ARE!

Many thanks to all who participated in the Conversation and Kris and Paul for leading it. We will go on to explore this topic further and the issues brought up.

CIICA.AISBL, June 2024