# MOVING ON WITH PERSON-CENTRED COCHLEAR IMPLANT SERVICES

## Insights from CI Users Across the Globe

## A CIICA Report

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# Moving On with Person-Centred Cochlear Implant Services: Insights from CI Users from Across the Globe


## Abstract

In 2021, the Cochlear Implant International Community of Action (CIICA) was established as a network of cochlear Implant (CI) users and potential users and other stakeholders including families, care providers, industry, public policy specialists and funders. Engagement has included innovative online conversations on topics identified by members; of particular interest among CI users has been the topic of person-centred care (PCC) for CI services and a series of Conversations on this theme took place, involving both CI users and professionals. Five conversations focusing on CI-related PCC were held over 14 months, attended by 77 adult participants in total from 19 countries. Overall, CI users reported they rarely received what they considered Person Centred Care. Attendees reported that CI care is often more likely to be centred on test results, protocols, clinic schedules, budgets, and the technology than on the person using the device. Attendees were consistent in their recommendations that person-centred CI services should involve the CI user in decision making, provide accessible information, include family and significant others, peer group support, routinely use Quality of Life measures and assess the centredness of CI services.


## Introduction

Hearing loss in adulthood has a far-reaching, and often unrecognized, impact on communication, mental and physical health, and employment opportunities (Shield, 2019; WHO, 2021). Persons who need more help than hearing aids provide for them may benefit from cochlear implants (CI), proven to be effective in improving communication, confidence and quality of life, as well as being cost-effective (Tang et al, 2024; Neve et al, 2021; Ng et al, 2016). However, access to CI varies globally, particularly for adults (Sorkin et al, 2016; Vickers et al, 2016; WHO, 2021). Reasons for limited uptake include fear, lack of awareness and support, practical inconvenience, social barriers, and systemic and organizational barriers (Bierbaum et al, 2020). Post-implant, the CI user requires lifelong management of the implanted device and the

externally-worn technology, and provision of rehabilitation, which is often underestimated (Archbold et al, 2023).

The adult CI International Consensus Statements (Buchman et al, 2020) made recommendations about CI services but did not consider ongoing rehabilitation. Clinical guidelines are in place for CI for adults (e.g., Cullington et al, 2023), but these rarely include the perspectives of users or family members. To learn more about CI users' lived experiences, a global consultation was conducted to explore the views of advocacy groups and individuals, including users, professionals, and industry, on advocacy for the management of hearing loss, and cochlear implantation (Archbold & Lamb, 2020). The major issues to emerge were the lack of CI user involvement in services and the lack of attention following surgery. A global health network was subsequently established, CI International Community of Action (CIICA), led by users and families in partnership with professionals and industry (Lamb et al., 2024). CIICA's goals are to support this network with the tools for change its members need to advocate for increased access to cochlear implantation and lifelong services. This network has more than 120 organisations and over 700 active individuals as members from 74 countries (CIICA, 2021; www.ciicanet.org).

Further research by CIICA with over 1,000 adult CI users responding from 40 countries revealed high levels of satisfaction with the impact of CI on communication, but also revealed wide variation in services, including limited rehabilitation, follow-up care, and challenges in maintaining the technology lifelong (Archbold et al, 2023). Håkansson Eklund et al (2019) reported a movement towards person-centred health care (PCC), putting the individual at the centre with their own individual qualities and context. Feldthusen et al (2022), reviewing person-centred services, considered that partnership, working with mutual respect, is key. However, this partnership was not often evident in their review of studies. Commenting on the lack of patient involvement, Feldthusen et al. further noted, "*It is remarkable that interventions that stress the involvement of patients do not ensure evaluations of what the patients find important are included"* (p. 898).

Consistent with its mission to be user- and family-driven, CIICA holds regular small-group online conversations on themes suggested by members, of interest to CI users, families and

professionals (Events – CIICA). A major theme has been Person-Centred Care (PCC) Adult CI Services and this paper summarises and explores issues emerging from five consecutive Conversations and proceeds to identify and discuss the most common themes and their implications for PCC in CI service policy and practice. With 1 million CI users (Zeng, 2022), over half of them adults, with growing evidence of the effectiveness of PCC, and while personalised rehabilitation and care is rarely considered important by adult CI services or guidelines, it is timely to explore what CI users themselves consider necessary in ensuring that CI services are person-centred.

**Methods**

From April 2022 to June 2024, CIICA held five small-group online conversations to explore members' experiences with Person-Centred CI services. Invitations for the Conversations were sent to network members and shared on the CIICA website (www.ciicanet.org). An average of 15 CIICA members attended five conversations (range 12–19). While the majority of participants were adult CI users, some professionals with an interest in person-centred services joined, including some working in the CI industry. The conversations were intentionally confidential, and no one was required to reveal personal information unless they chose to do so. Participants were from a total of 19 countries: Austria, Australia, Belgium, Canada, Finland, France, Germany, India, Ireland, Italy, the Netherlands, Portugal, Slovenia, South Africa, Switzerland, Turkey, Uganda, the United Kingdom, and the United States (see Table 1.)

Each conversation followed the same format, but introduced a different aspect of the theme of PCC in CI services, each building on the previous conversation. Each conversation was facilitated by the first two authors and one or two CI users. Conversations were limited to one hour with closed-captioning in English, as well as other languages upon request to provide accessibility. For each Conversation, the topic was introduced and a personal experience given to start the conversation by one of the facilitators. Conversations were not recorded to encourage free discussion and full participation, but a full transcript was made from the captioning. A Grounded Theory approach was used to analyse the transcripts by the first author to identify the emergent themes considered important by participants, rather than those previously defined (Dawes et al., 2024; Glaser & Strauss, 1967; Larson et al., 2019; Silverman,

2020). The transcripts and summaries were reviewed independently by the second author; comments and adjustments were made to reach consensus on the emergent themes. They were then reviewed again by all facilitators of each conversation to agree on the summary and then shared with participants and posted on the CIICA website.

Data were collected and stored in accordance with the General Data Protection Regulation (https://gdpr.eu/what-is-gdpr/). Participants registered voluntarily to take part in these conversations, and provided their name, contact email, country of residence and if a CI user. They were informed that a summary was to be made, including anonymised quotations. Continued participation was taken to indicate agreement to be quoted anonymously in the summary. Participants were able to comment on the summary before finalisation and dissemination.

Each of these topics related to PCC emerged from the conversations, with each conversation building on the previous (see Table 1).

**Table 1: Dates, topics and participants for five CIICA online conversations**

| Date | Topic | Participants |
|---|---|---|
| April 2022 | Adult Services After CI: Reimagining Rehabilitation | N=17: 13 CI users (2 =audiologists w/CI) 2 clinicians/educators; 2 considering CIs |
| February 2023 | Person-Centred Care in CI Services? | N=19: 12 CI users; 6 therapists/researchers; 1 awaiting implantation |
| September 2023 | Moving on with Person Centred Care in CI Services | N=14: 8 CI users; 4 clinicians; 2 family members |
| March 2024 | Person Centred Care: Measuring Quality of Life | N=12: 7 CI users; 3 clinicians; 2 family members |
| June 2024 | Person Centred CI Services: Can We Measure Them? | N=15: 7 CI users; 5 audiologists; 1 educator; 1 therapist; 1 public policy specialist |

The themes to emerge from each Conversation are presented, followed by a summary of the main themes. (Links to the detailed Conversation reports are provided in the Appendix.)

**Results**

Conversation 1: Adult Services After CI: Reimagining Rehabilitation

The first conversation was stimulated by a comment voiced by a CIICA member regarding CI services: *"CI rehab (rehabilitation) needs to be reimagined!".*

Participants were asked, "*What does 'reimagining rehab' bring to mind?"* They reported a wide range of experiences, from comprehensive post-implant rehabilitation and listening training to none. The group agreed that rehabilitation should always be available, regardless of where one lived. Additional recommendations included an easy-to-navigate pathway to services. This was reported by most as rarely available, with one attendee commenting, "*We should not have to search for services."*

Suggestions for rehabilitative practice included listening practice using audio books, podcasts, and music. Additional suggestions noted that rehabilitation should be 'bespoke' i.e., personalized, flexible, meaningful, and self-paced. As one user commented on finding on-line resources useful, *"I didn't have to rehab to someone else's schedule, I could rehab to mine."*

The value of including the family throughout was stressed by the group as hearing loss and its management affects communication with the whole family. In addition, the value of peer group support was stressed, as noted by one participant: "*You learn so much from other people's experiences."*

When the group was given the scenario, "*If you felt you had the right kind of rehab that you personally designed, and people [clinicians] listened to you, and respected your choices",* only one of the 13 CI users responded positively. There was strong support for the opportunity to co-create one's post-operative rehabilitation.

Key issues to emerge:

- Most CI users in the conversation considered they did not experience person-centred CI services.
- The majority of CI users considered they had to seek their own rehabilitation.

- They valued:
    - Listening training, including music;
    - The inclusion of family in rehabilitation services;
    - Peer-to-peer support.

Conversation 2: Person-Centred Care (PCC) in CI Services?

This Conversation followed the previous Conversation highlighting the lack of person-centred CI rehabilitation. To frame this conversation, sample definitions were provided (DiLollo and Favreau, 2010; Feldthusen et al, 2022; Granberg and Skagerstrand, 2022; Grosch et al., 2008): with person (and family-) centred care summarized as:

- responsive to an individual's preferences, needs, and values;
- ensuring one's values guide all clinical decisions;
- recognizing and valuing clients' knowledge and experience;
- is "more focused on the person rather than the task."

Several participants spontaneously agreed with the final definition; as one commented, "*Seeing the person as a whole, not just this person with a hearing loss."* One CI user considered that their team viewed their role as getting them implanted, programmed and then discharged, rather than lifelong care. Where person-centred experiences were reported, it was a full team effort focused on mapping, rehabilitation, and peer support, with collaboration. As one CI user described, *"[it was] lots of professionals working together at the same time."*

There were several examples where participants changed services and reported more positive experiences. When they had found an audiologist who was also a CI user, it proved particularly valuable: For example, *"I ended up finding a bilaterally implanted audiologist which has been such a gift because she has walked the walk."*

The suggestion was made that these appointments should include social and emotional issues as well as focussing on measuring hearing levels. One comment reflected their frustration: *It was just let's do the hearing tests so fast…undealt with emotions.* There were several comments that person-centred services should be available in the community – where CI users live and use

their CI in everyday life, rather than limited to the specialist CI centre. People welcomed the idea of appointments involving the issues met in everyday life, including families and the workplace.

Lack of support for adjusting to the changes in everyday life was a common theme:

*"When I got this implant, my whole situation changed… I was prepared to go back to the workplace with my functional limitations of what I can and can't do…[regarding] person-centred care, that must be a vocational issue that is not getting any attention."*

*"People are not prepared for the newfound capacity [after implantation]."*

*"I also needed to educate the people around me about my problem, about my hearing loss, and that was very hard."*

There were frustrations that services rarely involve the CI user in any decisions, including appointment scheduling:

"*My work is unimportant, the appointment comes first."*

"[I received] *a text message (about appointment time) which says don't reply to this message…"*

When asked how person-centred services should be facilitated, participants commented that they too need to take responsibility, "*They (audiologists) can't provide miracles. We must actively participate in the process…"*

To participate in the process, people agreed that they needed accessible information and to know what questions to ask. As stated by one user, *"I think there needs to be a way to empower recipients to know what questions to ask – a resource with what things you need to ask about."*

Peer groups and coaches were identified as valuable sources of information: *"I wish I knew then what I know now, but groups like you and online support and a coach I worked with was amazing."*

The importance of family involvement was a recurring theme. Family members are directly affected by the hearing loss and the CI process; they provide support and can recall information the CI user might have missed:

> *"My hearing husband has come to appointments… he does not totally get it from me, but when the hearing care provider says things he looks at that information in a different way."*

*"When emotions are involved in hearing loss, sometimes we don't express ourselves clearly."*

*"The strategies that myself as the person with a hearing loss, I need to share with my husband and the people in my life. ….. we don't communicate in a vacuum."*

Key issues to emerge:

- Positive experiences of PCC were often a result of changing services as well as building a good relationship.
- Audiologists who used a CI themselves were considered to have a particular contribution to make.
- CI users must also take responsibility: to do this, they need to understand the information provided.
- Services should incorporate teamwork and shared decision-making.
- Social and emotional issues involved in the change in hearing status should be addressed.
- Peer groups or coaches can support confidence at home, work, and society.
- Processes also need to be more person-centred, for instance collaborating on the scheduling, timing, and goals of appointments.
- PCC must include families.

Conversation 3: Moving on with Person-Centred Care in CI Services

The starting point for this conversation was a research article (Sturgiss et al, 2022) titled, "Who is in the centre of what? A scoping review of the conceptualization of 'centredness' in health care."

One CI user asked participants if their experience was person-centred with shared decision-making, and if families were included. As in earlier conversations, few participants confirmed positive experiences. Where experiences had been positive, it was often due to help from support groups and their own self-advocacy efforts.

*"I made it all about me and just asked for whatever I needed. Luckily the hospital I worked with were receptive to that… and I think that has made this whole journey a lot easier to get through."*

*"I think you don't realise how uncentred the care is until you find someone that puts you at the centre."*

"*They are flexible and able to accommodate what is needed and at first I was having trouble even wearing my device.*"

More reported less positive experiences, such as lacking information on expectations, available resources, or how to seek help if experiencing problems. As one user noted,

*"I didn't get a letter saying what I could do, what was available to me, where I could go if I suffered distress or if I felt sick after surgery."*

Others concurred and additional comments mentioned that processes were rigid and not individualized. Participants mentioned they needed courage to change clinics when dissatisfied, while others pointed out that they had no choice because of financial and process constraints.

*"I didn't even know the questions to ask."*

*"When I finally got brave enough to venture out of my assigned clinic, I ended up with a much more patient-centred focus … they were willing to invite me into the process."*

A CI clinician asked how CI centres could address their challenges of time, training and funding to develop person-centred services. Another clinician offered this approach, "*I try to say at the beginning of the session... what do you want to get out of this session, what is important to you, what are your goals?"*

CI users responded positively, emphasizing the importance of listening and involving the CI user in programming sessions. However, to be involved in decision making requires understanding information:

*"I think the most important thing to come up today is being informed."*

*"We need to provide access to information and services that isn't intimidating, this is why responsible [social media] groups, peer groups are so effective in providing appropriate information and allowing patients to raise their voices."*

<u>Key issues to emerge</u>:

- Positive experiences with person-centred services were shared but often had to be sought.
- In many systems there was no choice about the CI centre attended.
- Information about the purpose of the appointment was welcomed.
- CI users valued involvement in programming sessions, shared goal setting, counselling and support with real-life challenges.
- To be involved, people needed information; they needed to know what to ask and understand.
- Real life issues should be addressed as part of person-centred services.

Conversation 4: Person Centred Care: Measuring Quality of Life

In a prior conversation, the topic of Quality of Life (QOL) had emerged in the discussion on the impact of CI in everyday life. A CI clinician with expertise in QOL measures was invited to participate in this Conversation. The discussion began with a working definition of QOL: the degree to which an individual is healthy, comfortable, and able to participate in or enjoy life events. Given its subjective nature and reliance on self-report, QOL priorities are inherently personal. Participants were asked to comment on the following questions: What aspects of QOL are important to you and your family? Have they been measured?

One attendee noted *"for me, it definitely comes down to financial security,"* and others agreed. For some, their CI improved personal confidence through improved personal communication and interpersonal relationships.

*"I have the confidence that if I get into a difficult situation, I will be able to get out of it by having the communication skills I didn't have before."*

*"The biggest quality of life factor is getting my friends and family back."*

Although telephone usage was not directly questioned, it emerged spontaneously several times as a significant factor influencing the impact of CI on their QOL.

*"I didn't talk on the phone for years. I just kind of isolated… [now] I'm back there on the phone and I work wherever I want to work."*

*"My centre doesn't even know I use the phone. I've been using the phone for 22 years now. SO, how can we sell the idea of cochlear implants, get more people to invest in cochlear implants, when we don't even have that data?"*

Some mentioned that knowing about QOL measures was useful when advocating for oneself:

*"It's giving us a vocabulary, especially for those who feel not equipped to advocate, that we can at least enter the arena with the language."*

*"We need to make this information available in such a way that politicians and funders will understand and appreciate, and we can influence some of their decisions."*

Most reported no experience with QOL measurements: *"I've had my implant 22 years and I've never been asked."*

The few who reported being asked about QOL appreciated the opportunity to be heard. The invited clinician shared information about a validated QOL tool designed for and by CI users (McRackan et al, 2019); this ongoing development was valued and one attendee commented that it would be good to have a measure that included the QOL of their family too. The conversation ended on these encouraging notes: in some centres, CI users are being evaluated regarding QOL concerns, and this is valued by those who complete the measure.

<u>Key issues to emerge</u>:

- The characteristics defining "quality of life" are inherently personal.
- CI users reported improved financial security and confidence from improved communication.
- Measuring QOL by services was valued and helpful for CI users to participate in their own care.
- The consideration of measuring QOL brought up the possibility of measuring CI services overall, relative to person-centredness.
- Telephone use was valued by users, but not often considered by CI centres.

Conversation 5: Person Centred CI Services: Can We Measure Them?

Measuring PCC services emerged in the previous conversation, and this conversation began with an expert in patient clinical experiences (and also a CI user). He noted that a positive patient experience requires PCC, clear and consistent communication from all staff, scheduling that works for the patient, and other organizational processes meeting patient needs and preferences and mentioned the work of the Beryl Institute (Beryl Institute, 2025). Ways in which PCC could be provided and measured were introduced (Sommer 2024) and found helpful by the group to evaluate the service they had received and to compare in terms of PCC. The ongoing conversation illustrated the challenge of measuring PCC from the user perspective.

Issues about patient-clinician interactions emerged spontaneously after one user stated, *"Sometimes the audiologist is not focusing on the patient they are focusing on the computer,"* and another CI user commented,

*"They need to enter what they need to do (on the computer) … but they could say what they are doing…"*

One audiologist, also a CI user, noted "*As both a client and audiologist, I do an awful lot of typing, …. but my clients are sitting beside me and I have no problems with them seeing what is on the screen."*

Another audiologist commented, *"I think the best mapping (programming) allows you to share your experience."*

A CI user reinforced the feeling of not being listened to: *"My surgeon knew everything…he wouldn't listen… communication is difficult."*

Lack of choice related to CI services emerged again: "*There was not a choice of brand I went for – and I had two choices of colour – brown or beige… some things are budget-centred."*

Several participants agreed that effective communication was a challenge: those with CI have a significant hearing loss and hence communication challenges if, for example, the processor is removed for testing in the clinic.

Knowing the questions to ask the professional can be challenging as people don't know what they don't know. The comment that "*Sometimes people are intimidated by the service,"* highlighted the challenge some face in communicating with professionals about their care or

needs. The suggestion that *"Somebody needs to write the definitive guide for CI candidates,"* received widespread agreement.

Key issues to emerge:

- Participants valued the opportunity to consider the services they had received from a PCC point of view and reported CI services ranging from very good to poor.
- A lack of choice in service provision.
- Need for patient empowerment with accessible information.
- CI users valued their involvement in appointments and decisions.

**The Most Common Themes to Arise from the Five Conversations:**

- Most CI users considered that they don't receive person-centred services.
- There was considerable consensus about what PCC involves:
    - Shared communication
    - Mutual respect
    - Partnership in decision-making
    - Choice on a range of levels, including the service, device, appointments, and rehabilitation
- Where experiences were positive, CI users had often sought them out.
- Adults needed comprehensible information before and after implantation to enable them to be involved in their own care and decisions.
- There was a lack of choice in decisions to be made.
- The impact of CI on QOL, and the changes experienced after CI including home, social life and work was not routinely addressed, recognized, or measured.
- Social and emotional issues were not addressed.
- Peer-to-peer support and family involvement were considered important and often excluded from the service.

## Discussion

While participants were not randomly selected, they were of a wide age range, with varied experiences, and from different countries with differing practices and systems. Across the five Conversations, consistent issues emerged and were repeated, by a range of users, giving some basis for face validity of the emergent issues.

The term "person-centred care" was consistently used throughout the five Conversations, intentionally bypassing the term "patient-centred care." As Håkansson Eklund et al. (2019) noted in their "review of reviews," these two terms are often used interchangeably but in fact represent different goals:

- the goal of patient-centred care is to support *a functional life* as defined by clinicians and determined by test results;
- the goal of person-centred care is to support *a meaningful life***,** as defined by the recipients of care and their families.

The issues emerging from these Conversations reveal CI users' goals for a meaningful life as well as a functional one.

The concept of "centering" was itself a topic. In an analysis of 159 papers, Sturgiss et al (2022) identified nine aspects of centredness, all of which were mentioned as important to participants in the first two Conversations. However, attendees added 'budget-centredness' (Table 2), based on experiences of brief appointments, with little time for exploring QOL or the CI user's priorities.

**Table 2: Competing "Centredness" Models in CI Care (adapted from Sturgiss et al., 2022)**

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

Experiences of person-centred care

The most common issue to emerge was the perceived lack of person-centred services with most participants reporting that they had not experienced this type of care. They reported a lack of choice, in regard to the service attended, the brand of device received, type and colour of processor, and lack of choice about appointments and support. They also reported a lack of recognition of the issues which were most important to them: the changes in their functioning in everyday life and how to maximise the benefits of CI.

Cochlear implantation has a major impact on one's communication in everyday life, and therefore one's everyday functioning and relationships. In Ng et al's (2016) report of 149 adults, the need for communication support significantly decreased after CI, with the percentage of participants reporting "none required" rising from 44% to 66%, resulting in greater independence. Furthermore, when asked about telephone use, 7% reported using the telephone "a lot" before CI and 28% after CI. Although telephone usage was rarely discussed by professionals, CI users in the Conversations spontaneously reported that to be able to use the telephone was a significant and positive change in their lives. For this group, their services were more often clinician-centred and protocol-driven rather than exploring the issues important to users.

Where experiences had been positive regarding PCC, participants had advocated for themselves and sought services out; to do this, one needs to be confident and to know what the important issues are to seek.

Participating in one's own care

Patients wish to be involved in their own care (Bernstein et al., 2021; Illg et al., 2022), as recommended by WHO (1977) and the World Report on Hearing (WHO, 2021), and wish to have the opportunity to improve their satisfaction and health outcomes (Håkansson Eklund et al, 2019). Athalye et al. (2015) found that CI users wished for decisions on CI care to be user- and family-driven and for more services to be delivered in the community, where they used the CI for daily communication at home and work.

Receiving a CI provides adults with increased confidence in communication and autonomy, the confidence "to stand up for themselves," and the ability to participate in decision-making (Hübner et al 2022). This group expressed satisfaction when they sought a service suited to their needs or had opportunities to change services. Hibbard and Gilburt (2014) also noted that patient activation, along with knowledge, skills, and confidence to manage one's own health, is closely linked to better clinical outcomes and an improved patient experience. Similarly, Archbold et al. (2023) observed greater satisfaction among individuals who self-initiated rehabilitation, engaged in informal support from family and friends, or participated in peer groups and CI organizations as recommended in the Living Guidelines (CIICA, 2022). Attention to care from the patient's perspective has been found to result in improved patient self-management, higher rates of adherence to recommendations, and overall better health outcomes (English & Archbold, 2014).

Given the lifelong commitment, and the ethics of implanting a device within the body, the need for clear information is evident (Rapport et al, 2020; Schulz et al, 2023). Hübner et al. (2022) note the challenges of obtaining and understanding up-to-date complex health and technical information, the conflicts of industry involvement in CI. A lack of readable information in CI brochures has been identified (Looi et al, 2022; Ng et al, 2016). Reliance by CI clinics on industry literature, while technologically accurate, may not be easily understood by potential CI candidates or users, or non-specialist professionals (Archbold et al 2023). Rapport et al (2020) reported that non-specialist professionals are often not well-informed about CI, despite being involved in the process of referral and decision making. They recommended that professional education about CI is also provided for non-specialist professionals. Schulz et al. (2023) recommended the patient perspective be included to ensure that information is transparent and understandable; the participants in these groups proposed that CI users develop their own 'handbook' of the information provided.

Barriers to Delivering and Receiving Person-Centred Services

The following perceived barriers to the delivery and receipt of person-centred services were identified:

- Finance and sustainable services
    - Cochlear implantation is a process which requires funding of various elements: assessment and implantation, ongoing fitting of the device, rehabilitation and technical support, and replacement parts. The participants observed the financial pressures felt by professionals influencing the services received. Where systems utilise government or other third-party funding, including insurers, there may be limits placed on funding for cochlear implantation and associated services or equipment. These financial commitments are inherited by CI users due to the long-term maintenance needs, and the continuous functionality of their device, major causes for concern which can lead to non-use if not addressed. (Archbold et al, 2023).
- Staff resources and training
    - Time was a barrier reported by audiologists as being an issue in not utilising a more PCC approach (Warren and Barron, 2024) and this pressure on CI professionals was observed in the Conversations. While many professionals may feel pressured within a target-driven healthcare system, a more person-centred approach addressing the CI user's concerns could take less time in the long run, with potentially a more positive impact to the user's outcomes, as well as securing greater trust and compliance with the care plan (English 2008). Although required to demonstrate continuing education, training in PCC and the support of social and emotional challenges for those working within CI services are lacking.

      Warren and Barron (2024) reported audiologists being aware of the benefits of psycho-social interaction with adults in their CI clinics, but over 90% never screened their patients for psycho-social issues and less than half made referrals to a psychologist. Lack of time and confidence in counselling skills were reported as barriers to screening or making a referral.
- Lack of accessible information prevents partnership working
    - CI involves highly technical, changing information. Participation in one's own decision relies on information provided in an accessible format and in an environment promoting partnership, addressing any communication needs to ensure full

accessibility. This has been identified as a barrier to decision-making in this and other studies (Muscat et a., 2022; Rapport et al., 2020).

- Systemic barriers and lack of coordination of the complex processes of CI
    - The coordination of CI care and support involves professionals from diverse backgrounds in diverse systems with different processes; for example, healthcare and education, clinic-based and community-based. CI services include various professionals with differing priorities and perspectives, adding complexity to consistent information and decision-making in a multi-professional group. Rapport et al (2020) commented on the complexity of CI processes which hinder the journey of adult CI candidates and users, and recommended simpler systems. Furthermore, poor communication and coordination among these professionals can make it harder to provide cohesive, person-centred effective care as evidenced in reported systemic failures (e.g., Meacham, 2023).
- Delivering person-centred CI services
    - In order to overcome these barriers, Feldthusen et al (2022) suggested the following strategies with regard to PCC: listening to patients' experiences, sharing information and goals, and welcoming the patient and/or the patient's significant others to be part of the team. They also consider the balance required to ensure the professional acts in a professional manner, with significant expertise, while valuing the patients' input. This assumes that the above barriers, such as training and finance are addressed. Feldthusen et al (2022) also recommend ongoing evaluation of both centredness and its impact: this was endorsed by the participants and a suggestion in Conversation 5.

**Conclusion**

The five Conversations revealed that person-centred CI services remain more aspirational than reality for many adult CI users. When experienced, such services were often the result of the users' own advocacy efforts including finding professionals who were themselves CI users. While the participants represented a self-selected group, their consistent experiences across different healthcare systems suggest broader implications for improving CI care globally.

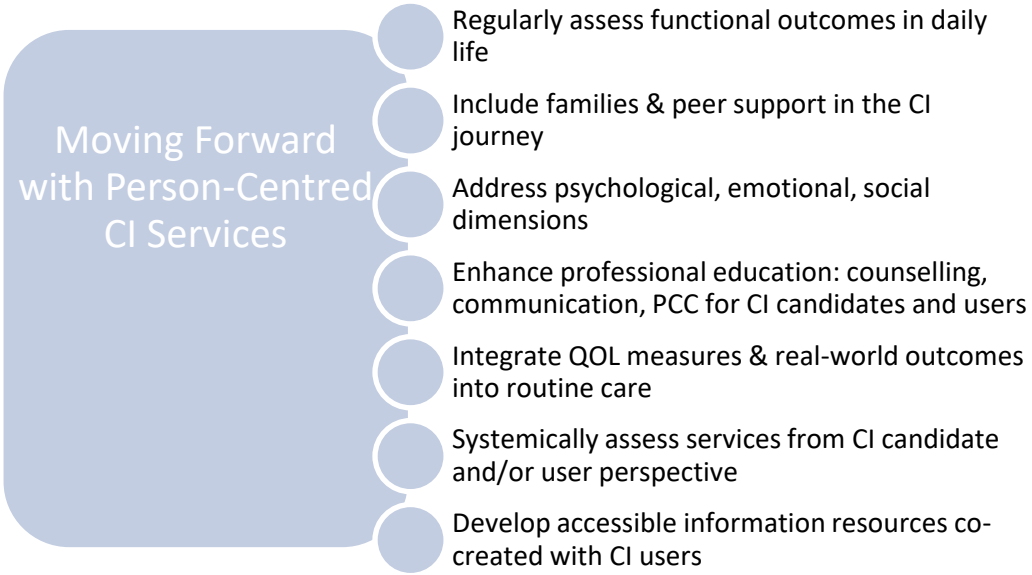
Most participants indicated that current practices often prioritize technical and clinical priorities over a holistic approach that considers individual needs, preferences, and life circumstances. The participants clearly articulated what person-centred CI services should encompass: shared decision-making, mutual respect, partnership in care, choice at multiple levels, involvement of family and peer group, and recognition of the profound impact of CI on QOL and psychosocial issues across home, work, and social domains.

Several key barriers to implementing person-centred CI services emerged: resource limitations, financial constraints, time limitations, lack of accessible information, insufficient professional training, sustainability concerns, and systemic barriers in coordinating complex CI processes. These barriers point to opportunities for improvement at both the clinical and systemic levels.

Moving forward requires several fundamental changes, as depicted in Figure 1 below.

**Figure 1:**

**Fundamental Changes Needed to Move Forward with Person-Centered CI Care**




As the global CI user population continues to grow, it is imperative to ensure services are more person-centred. The experiences shared in these Conversations suggest that

doing so could lead to better outcomes and greater satisfaction for CI users while potentially improving the efficiency and effectiveness of service delivery. Future research should focus on developing and validating tools to measure person-centredness in CI services and for CI teams to implement an evaluation of the impact of person-centred approaches on CI user outcomes.

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**Appendix: Links to the individual Conversation summaries**.

Conversation 1: Adult Services After CI: Reimagining Rehabilitation: https://ciicanet.org/wp-content/uploads/2022/04/CIICA-Conversation-4-Adult-Services-After-CI-Reimagining-Rehabilitation.pdf

Conversation 2: Person-Centred Care in CI Services? https://ciicanet.org/wp-content/uploads/2023/02/CIICA-Conversation-8-Person-Centered-Care-in-CI-services.pdf

Conversation 3: Moving on with Person-Centered Care in CI Services: https://ciicanet.org/wp-content/uploads/2023/08/CONVERSATION-MOVING-ON-WITH-PERSON-CENTRED-CARE.pdf

Conversation 4: Person-Centred Care: Measuring Quality of Life: https://ciicanet.org/wp-content/uploads/2024/07/CIICA-Conversation-PCC-7-March-2024-summary.pdf

Conversation 5: Person-Centred CI Services: Can We Measure Them? https://ciicanet.org/wp-content/uploads/2024/07/CIICA-Conversation-PCC-26-June-2024-summary.pdf