

A New Question Prompt List for Persons Considering Cochlear Implants

By Kris English, PhD and Sue Archbold, PhD, Hon LLD, MPhil

When individuals with severe hearing loss begin to consider cochlear implants (CI), one logical step is to search the internet for information. For example, a recent report identified the most frequent topics posed to a popular search engine about cochlear implants, specifically technical details about devices (most advanced CI, life expectancy, etc.), surgical factors (pain/risk), and the postoperative experience (length of hospital stay).¹

These questions represent the beginning of a journey, but questions regarding more pragmatic concerns may be difficult to articulate when the topic is unfamiliar. Cochlear implantation involves a range of professional disciplines with complex information to navigate. Given the lifelong commitment and the ethics of implanting a device within the body, the need for clear, understandable information is evident.^{2,3} In spite of the effectiveness and cost-effectiveness of CI in adults, there remains a significant gap in uptake of cochlear implantation, with only 1 in 20 candidates globally receiving an implant.⁴⁻⁶

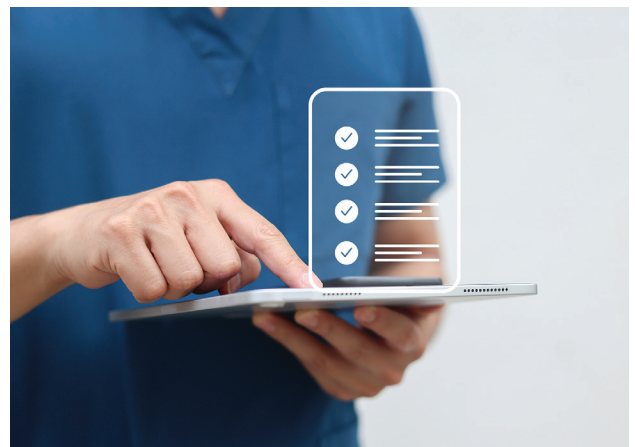
The development of a Cochlear Implant Question Prompt List (CI QPL) arose from the concerns of CI users emerging in global conversations on person-centred care about the lack of accessible information.⁷ Over the course of more than two years, we learned via direct input from dozens of CI users that the experience of “not knowing what to ask” was a common issue as well as having a strong interest in developing a question list to help others.

What is a Question Prompt List?

Question prompt lists (QPLs) resemble frequently asked questions information sheets but focus on asking questions—not providing answers. QPLs are communication aids created to encourage patients and families to actively participate in discussions by helping them choose the questions(s) they would like to discuss at any given appointment. Brown et al. note that “a QPL can successfully encourage patients to ask questions about topics that are known to present significant difficulties during consultation discussions.”⁸ QPLs have been used in patient care for over 30 years across a range of health conditions.⁸⁻¹¹

DEVELOPING THE COCHLEAR IMPLANT QPL

Like the development of most QPLs, this project began with input from individuals directly affected by a health condition—in this case, adults with permanent hearing loss living with



cochlear implants. These individuals (from 21 countries) were members of the Cochlear Implant International Community of Action (CIICA, ciicanet.org) who attended a series of nine Zoom conversations from February 2023 to May 2025, addressing the overall theme of person-centered care. Attendees included CI users, professionals involved in CI, and researchers. Topics were informed by attendees' input during ongoing conversations, including “What Do You Wish You Had Known Before CI?” and “Nobody Told Me What to Ask,” and led by CI and HA users, with an audiologist. (A complete list of conversation topics is available here: <https://ciicanet.org/events/list-of-summaries> under the heading “Person Centered Care.”)

Each one-hour conversation was recorded, transcribed, summarized, and reviewed for clarity and accuracy, agreed by the facilitators, and then posted on the CIICA website. A few themes became readily apparent, especially regarding “questions I wished I had asked, or didn't know how to ask” before cochlear implantation. Attendees explicitly identified a need for sample questions to take to appointments. In response, from the transcripts the authors identified all “I wish I had known to ask” questions and then invited attendees to participate in a consensus process by first reviewing and then prioritizing the most frequently mentioned (“Top 20”) items. The final version (see Appendix) was assessed for readability with an online Flesch-Kincaid calculator (<https://serpinja.io/tools/flesch-kincaid-calculator>), indicating 6th grade reading level/ “easy,” as recommended by the National Institutes of Health.¹²

DISCUSSION

Cochlear implantation involves complex health and technical information which is challenging for both professionals and those with hearing loss; however, written materials (e.g., brochures) typically do not contain easy-to-read information.^{13,14} Industry literature, while technologically accurate and readily available, may not be easily understood by potential CI candidates or users or non-specialist professionals, and there may be conflicts of industry involvement in providing CI information.^{15,16} Non-specialist professionals are often not well-informed about CI, despite being involved in the process of referral and decision making, leading to individuals being referred for CI without preparation for the process.² Schulz et al. therefore recommended the patient perspective be included to ensure that information is transparent and understandable; the participants in this project ensured that the CI prompt lists were accessible to a wide group.³

There is a difference in the questions posed to a search engine compared to questions recommended by CI users based on their lived experiences.¹ Levi et al. provide some insights: their analysis of 80 CI websites found content to be “highly heterogeneous,” and presented at a “hard to read” literacy level.¹⁷ Even when readable, the generic nature of the posted information can make it difficult for patients to ask what they really want to know.

Patients wish to be involved in their own care, as recommended by the World Health Organization’s *World Report on Hearing*.^{17,18} Hibbard and Gilbert also noted that patient activation, with knowledge, skills, and confidence to manage one’s own health, is closely linked to better clinical outcomes and an improved patient experience.¹⁹ The use of the CI QPL during the assessment process involves patients with their care from the outset. 

CONCLUSION

The CI QPL meets an identified need with user-recommended questions provided at a recommended reading level and has the potential to give patients confidence to increase question-asking as well as information recall.^{12,20} It can be downloaded from the CIICA website: <https://ciicanet.org/resources/considering-a-cochlear-implantci-20-questions-to-ask-a-prompt-list/>

Kris English is Professor Emeritus of Audiology at the University of Akron. She is the co-author of *Counseling-Infused Audiologic Care* (4th ed) and can be reached at ke3@uakron.edu.

Sue Archbold is a teacher of the deaf, who coordinated Nottingham CI program from its inception, then The Ear Foundation with programs of family support and information, education and qualitative research. She is Coordinator of CIICA.

The authors have disclosed no financial relationships related to this article.

Appendix

Considering A Cochlear Implant (CI)? Questions to Ask:

Recommended by members of the Cochlear Implant International Community of Action (CIICA) to think about when being assessed for cochlear implantation. They were agreed in a series of Conversations by CI and hearing aid (HA) users, families and CI professionals following discussions on the theme of “what I wish I had asked, and what I wish I had known before CI.”

About CI devices and surgery:

1. Do I have a choice of CI? If so, what do I need to know to choose the CI that would be right for me?
2. Can I wear an HA with the CI? Do you provide two CI?
3. What are the costs I can expect? How are the costs of batteries, repairs, and replacements funded?
4. Will there be a lot of pain? Risks of operation? Care of wounds?
5. How long is typical recovery time from surgery/when would I be able to return to work?
6. Who will I contact if I am worried after the operation?
7. Do you test my balance? Will it be affected?
8. I have tinnitus—will it be affected? Does CI cause tinnitus?

About rehabilitation and follow up:

9. What appointments will I need after the operation and when I get the processor fitted? How much time will this take out of work during the first year after CI?
10. What sort of rehabilitation or training and practice will I need, and get, to help adjust to the new sound and to manage the technology?
11. Is rehabilitation provided by your clinic, or do I have to arrange for my own rehab? If the latter, do you have a list of recommendations?
12. Does rehabilitation involve additional out-of-pocket costs? If so, how much?
13. How will I know if the implant or processor are working properly? What do I do if I am concerned?
14. How soon will I be able to understand speech?

About support systems:

15. Can I meet others who have had an implant? Can my family talk to them too?
16. Would you be OK with including my family in my appointments?
17. Is there a local support group?
18. Will any counselling be provided?
19. What support is available to learn how to link to my phone or TV and to use any assistive listening devices?
20. Do you have any information I can take to read or any helpful websites you can direct me to?

REFERENCES

1. Benaim EH, O'Rourke SP, Dillon MT. What do people want to know about cochlear implants: A Google analytic study. *The Laryngoscope*. 2025;135(2): 840–847.
2. Rapport F, Hughes S, Boisvert I, et al. Adults' cochlear implant journeys through care: A qualitative study. *BMC Health Services Research*. 2020;20(1): 457.
3. Schulz S, Harzheim L, Hübner C, et al. Patient preferences for long-term implant care in cochlear, glaucoma and cardiovascular diseases. *International Journal of Environmental Research and Public Health*. 2023;20(14):6358.
4. Archbold S, Mayer C, Lamb B, et al. *Cochlear implant services matter: Cochlear implants in deaf and deafened adults: A global consultation on lifelong aftercare*. Accessed February 17, 2026. <https://ciicanet.org/wp-content/uploads/2023/11/CI-SERVICES-MATTER-REPORT-1-1.pdf>.
5. Tang D, Tran Y, Lo C, et al. The benefits of cochlear implantation for adults: A systematic umbrella review. *Ear and Hearing*. 2024;45(4):801–807.
6. D'Haese P, Van de Heyning P, Gavilan J, et al. Trends in adult cochlear implant access and uptake across ten years of reported data. *Audiology Research*. 2026;16(1):19.
7. Beirbaum M, McMahon Hughes C, Hughes S, et al. Barriers and facilitators to cochlear implant uptake in Australia and the United Kingdom. *Ear and Hearing*. 2020;41(2):374–385.
8. Brown RF, Bylund CL, Li Y, et al. Testing the utility of a cancer clinical trial specific Question Prompt List (QPL-CT) during oncology consultations. *Patient Educ Counsel*. 2012;88(2):311–317.
9. Butow PN, Dunn SM, Tattersall M. Patient participation in the cancer consultation: Evaluation of a question prompt sheet. *Annals Oncol*. 1994;5(3):199–204.
10. Clayton J, Butow P, Tattersall M, et al. Asking questions can help: Development and preliminary evaluation of a question prompt list for palliative care patients. *Brit J Cancer*. 2003;89:2069–2077.
11. English K, Walker E, Farah K, et al. Implementing family-centered care in early intervention for children with hearing loss: Engaging parents with a Question Prompt List. *Hearing Review*. 2017;24(11):12–18.
12. National Institutes of Health. (n.d). Clear and simple. Available from: <https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication>. (accessed February 2, 2026).
13. Looi V, Boulton R, Timmer B, et al. The suitability and readability of cochlear implant information brochures for potential adult recipients. *International Journal of Audiology*. 2022;61(4):293–300.
14. Ng Z, Lamb B, Harrigan S, et al. Perspectives of adults with cochlear implants on current CI services and daily life. *Cochlear Implants International*. 2016;17 Suppl 1, 89–93.
15. Hübner C, Lorke M, Buchholz A, et al. Health literacy in the context of implant care-perspectives of (prospective) implant wearers on individual and organisational factors. *International Journal of Environmental Research and Public Health*. 2022;19(12):6975.
16. Levi A, Leinung M, Helbig S, et al. Thematic coverage and readability of online patient information on cochlear implant care. *European Archives of Oto-rhino-laryngology*. 2024;281(9):4727–4734.
17. Ilg A, Bräcker T, Batsoulis C, et al. CI decision making and expectations by older adults. *Cochlear Implants International*. 2022;23(3):139–147.
18. World Health Organization. (2021). *World Report on Hearing*. Available at: <https://www.who.int/publications/i/item/9789240020481>.
19. Hibbard J, and Gilbert H. *Supporting people to manage their health: An introduction to patient activation*. London: The King's Fund. 2014. https://assets.kingsfund.org.uk/f/256914/x/d5fbab2178/supporting_people_manage_their_health_2014.pdf.
20. Ey JD, Herath MB, Reid JL, et al. Improving communication and patient information recall via a question prompt list: Randomized clinical trial. *British Journal of Surgery*. 2023;110(12):1793–1799.