

COCHLEAR IMPLANT SERVICES MATTER

A global consultation: What services do deaf and deafened adults with cochlear implants get and what do they want?

CONTEXT:

- 1.5 billion people live with some form of disabling hearing loss (*WHO, 2021*)
- Unmanaged hearing loss has a massive unrecognized impact on communication, social, emotional, cognitive and physical well being (*WHO, 2021*)
- Hearing loss is highest cause of Years Lived with Disability over 70 (*Lancet 2021*)
- Globally, unmanaged hearing loss costs US\$ 980 billion annually (*WHO, 2021*)
- Cochlear implantation is effective and cost-effective in providing useful hearing (*Archbold et al 2015, Lamb et al 2018, WHO, 2021*)
- Cochlear implantation involves the process of assessment, surgery to implant internal device, the fitting and maintenance of the external speech processor and rehabilitation
- Wide variation in access and use, and little research on services needed.

WHAT WE DID: THE SURVEY

- Global online survey with open and closed questions
- CI users involved in the development
- Translated into six languages
- 1076 respondents from 40 countries
- Respondents aged 18-91 years of age
- Aged a few months to 88 years at implantation

WHAT DID PEOPLE TELL US?

Overall, high satisfaction with CI:



“ Super satisfied: the best decision of my life. ”
CI User

Overall, high satisfaction with Services:



“ I hit the jackpot with my audiologist and doc – they rock! ”
CI User

Fragmented funding: for different parts of the service by different service providers

Rehabilitation Services:



Spares:



Processor:



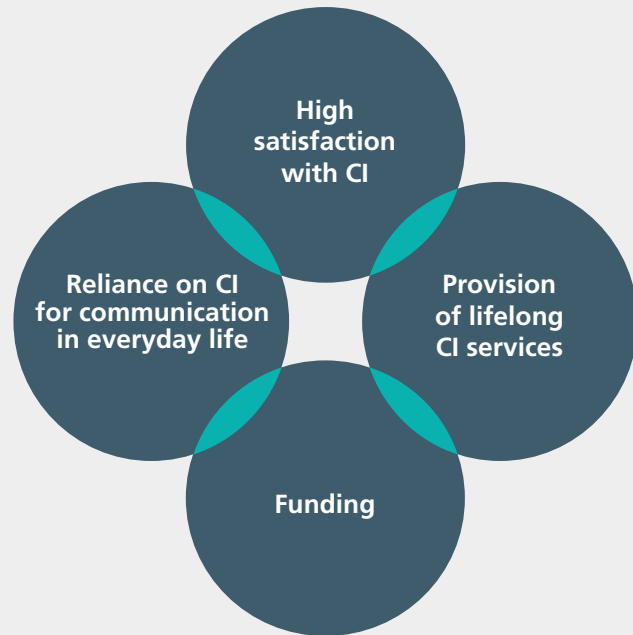
“ It would have been nice to have some support. I had no rehabilitation – I taught myself everything. ”
CI User

Personal Payment:



“ We wish the high prices for our CIs would come down, it is impossible to get new accessories, new processors. ”
CI User

Satisfaction with CI requires funded lifelong services



ADULTS WERE MORE SATISFIED WHEN:

- Regular appointments – for both technology management and rehabilitation
- Easy, quick access to technology support
- Access to technology upgrades, bilateral CI, spares
- Person centered collaborative care, including peer groups, CI groups, counselling services
- Access to informal therapy, self-initiated therapy

GREATEST CONCERNS:

- Daily concern if technology breaks down
- Needing lifelong service
- Funding

RECOMMENDATIONS:

- Access to CI services needs to be built into plans for Ear and Hearing Care.
- Awareness of the benefits of CI and referral criteria should be increased amongst those deaf and deafened, professionals, the general public, and public health decision makers.
- Lifelong CI services should:
 - Include at least 4-6 programming sessions in the first year after surgery, and 2-3 sessions per year up to five years after surgery.
 - Include rehabilitation from the beginning as part of the core provision of implant services.
 - In the long-term, include at least one appointment annually, to monitor progress and provide a technology check.
 - Include quick and ready access to technology support when required, including spare parts such as processors, cables and coils, regular processor upgrades.
 - Provide access to bilateral cochlear implants where appropriate.
 - Be person-centred, with access to appropriate peer group support and counselling services
 - Provide information in accessible formats, promoting health literacy and patient involvement in their own care.
- Funding must be provided to ensure sustainability of services and access to support throughout the life course.

REFERENCES:

WHO World Hearing Report 2021.
<https://www.who.int/publications/i/item/world-report-on-hearing>
The Lancet (2021). Hearing loss prevalence and years lived with disability, 1990–2019: findings from the Global Burden of Disease Study 2019. VOLUME 397, ISSUE 10278, P996-1009, MARCH 13, 2021 DOI:[https://doi.org/10.1016/S0140-6736\(21\)00516-X](https://doi.org/10.1016/S0140-6736(21)00516-X)

Archbold, S., et al., (2015). The real cost of hearing loss. Nottingham, England: The Ear Foundation. Available from www.ciicanet.org/resources

Lamb, B, Archbold S, O'Neill C (2018) Investing in hearing technology improves lives and saves society money. www.ciicanet.org/resources

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Thanks to all our respondents and the CIICA network.

For further information about cochlear implantation go to [Cochlear implants - Hearing Link Services](#).



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I'll be reliant on it for the rest of my life.

CI User