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 guestions
- 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: **72% 24%** 4% **VERY** NOT **SATISFIED SATISFIED SATISFIED**

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

Overall, high satisfaction with Services:

VERY SATISFIED

56% 40% SATISFIED

NOT **SATISFIED**

4%

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: **32**% **NOT ENOUGH 27%**

Spares: 11% **NO SPARES AT ALL**

Processor: 26% NO SPARE

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

36%

PAY FOR REPAIRS

Personal

Payment:

49% PAY FOR BATTERIES

ACCESSORIES

PAY PERSONALLY

FOR SPARE PARTS

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

CI User



High satisfaction with CI requires funded lifelong services Reliance on CI for communication in everyday life Funding Funding

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

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

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



Authors: Sue Archbold, Connie Mayer, Brian Lamb, Imran Mulla.

Email info@ciicanet.org The full report visit www.ciicanet.org

Thanks to all our respondents and the CIICA network.

For further information about cochlear implantation go to <u>Cochlear implants - Hearing Link Services.</u>

This project was a partnership between York University in Toronto, Canada and the Cochlear Implant International Community of Action (CIICA) – ciicanet.org, supported by a grant from the Social Sciences and Humanities Research Council, Canada.

education



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.

"

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

CI User