

OUR REPORT: CI SERVICES MATTER?

- This is the first global report on what adults with CI get and would like
- Our Report contains not only the figures, but the analysis of the 3,000 free responses

COCHLEAR IMPLANT SERVICES MATTER

Cochlear implants in deaf and deafened adults:
A global consultation on lifelong aftercare

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

A partnership between York University in Toronto, Canada and the Cochlear Implant International Community of Action (CIICA).
Grant: Social Sciences and Humanities Research Council, Canada, via York University, Toronto.

education | YORK U



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:

36% PAY PERSONALLY FOR SPARE PARTS

29% PAY FOR REPAIRS

54% PAY FOR ACCESSORIES

49% PAY FOR BATTERIES

“ 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:

72%

VERY
SATISFIED

24%

SATISFIED

4%

NOT
SATISFIED

Satisfaction Rates

High Satisfaction with CI Services:

56%

VERY
SATISFIED

40%

SATISFIED

4%

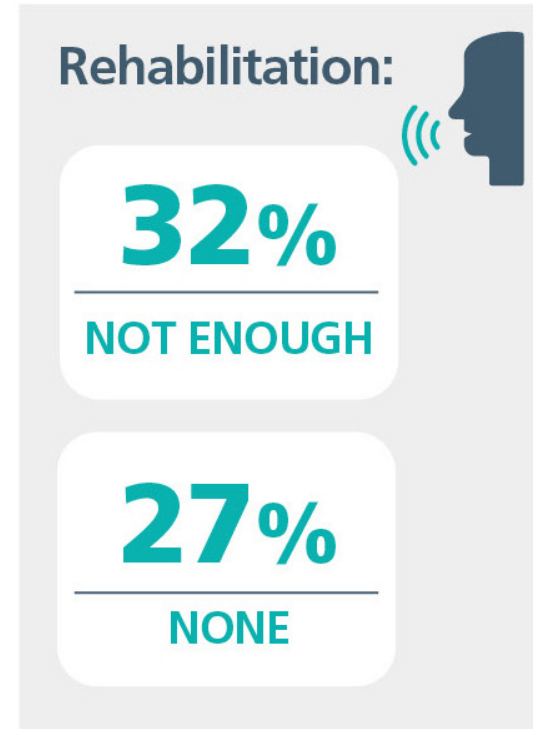
NOT
SATISFIED

Rehabilitation services for adults?

- **27% had none at all..**
- **54% had none after the first year**

The team only focusses on medical and audiology parts. Nobody guides you to audiology therapy or user groups. (Belgium, 67)

- *I believe I would have benefited from rehab services and was disappointed that it was simply not considered a part of the whole process for adults, as rehab is for children. (USA, 56)*
- *Think initial implant training is lacking across all areas. They leave you somewhat abandoned. (Spain, 39)*



**What
increases
satisfaction?**

Public funding

Bilateral CI

Regular checks

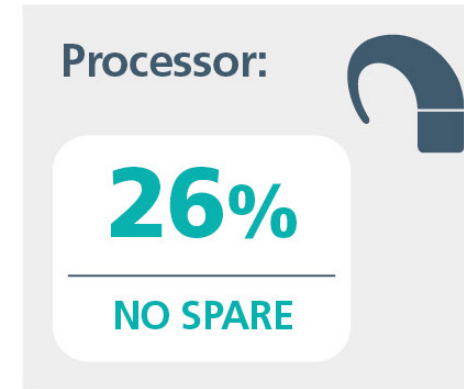
Access to technology, spares and upgrades

Rehabilitation from the start

Including peer group support, belonging to CI group

Technology support matters

- *Impossible for me to be in crowds and restaurants. (France, 45)*
- *In case of technical problem or in using the device, it is hard to cope alone, hard to know who to go to in order to solve a problem. (France, 62)*
- *Users become totally dependent on the device so we need assurance that we can get timely repairs, and also that any updates to the programming are of suitable quality. (Australia, 49)*
- *When it breaks down I really suffer and isolate myself. The response times to failure and breakdown are slow. (Spain, 33)*



Who funds the services?

Service	Public/Govt	Private Health	Charity/NGO	Personal
1st Implant	62%	35%	2%	9%
2nd Implant	48%	40%	1%	14%
Mapping	67%	24%	3%	10%
Rehabilitation	63%	20%	3%	16%
Repairs	50%	22%	2%	29%
Spare Parts	50%	22%	2%	36%
Replace Pro	50%	22%	2%	26%
Upgrade Pr	50%	22%	2%	16%
Streamers, Accessories	35%	16%	1%	54%
Batteries disposable	38%	13%	2%	49%
Batteries rechargeable	44%	20%	1%	41%

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



Funding.... A major issue even in high income countries: personal funding

- *Costs are unaffordable (Mexico, 25)*
- *We wish the high prices for our CIs would come down, it is impossible to get new accessories, new processors, etc (Spain, 33).*
- **COSTS CAN EVEN LEAD TO NON-USE:**
 - *Difficulty exchanging [the CI] when it was obsolete, and family members did not have the income to buy [a new one]. (Brazil, 1)*

Personal Payment:



36%

PAY PERSONALLY FOR SPARE PARTS

29%

PAY FOR REPAIRS

54%

PAY FOR ACCESSORIES

49%

PAY FOR BATTERIES

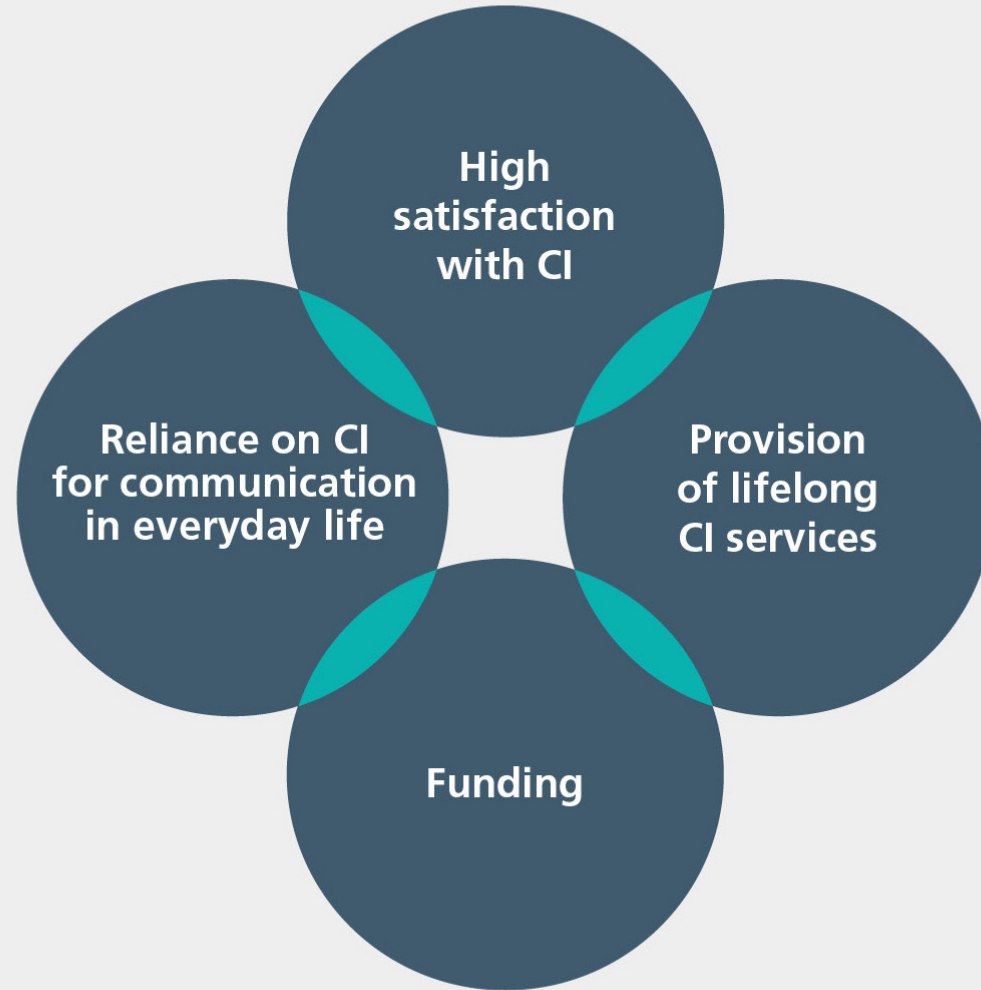


Funding.... For young adults... a lifetime's use will be a long time..

- *Once implanted, especially at young ages, there are lifelong costs and since being implanted so young it's very possible there could be a need for reimplantation if the device fails after 30-40 years or longer.*
- *Many people get their cochlear implants later in life when they may have 20 years to live or less but not me. I may have mine for 80 or more years. I've already had them 19 years so I'm facing struggles and issues the older generation knows nothing about; I've always heard through a cochlear so it's all I know. (USA,2)*
- *See Jess later!*

Satisfaction with CI requires funded lifelong services

SO.....



CIICA's Briefing to share... translations? full report at www.ciicanet.org/news

- **Key messages:**
- Access to CI must include access to funded lifelong CI services
- Funding must not rely on personal funding
- Rehabilitation must be included from the start
- Access to technology support, upgrades and spares
- At least annual checks long term
- Peer group support, counselling services to be included
- *You can save yourself the question: I'll be dependent on it for the rest of my life. (Germany, 12)*

COCHLEAR IMPLANT SERVICES MATTER

A global consultation: What services do deaf 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 980 \$ 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 process of assessment, surgery to implant internal device and the fitting and maintenance of the external speech processor
- 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?

