

Cochlear Implants in Deaf and Deafened Adults: A Global Consultation on Lifelong Aftercare

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Rationale

- ❑ Current global guidelines (Buchman et al, 2020) do not address the lifelong care necessary for both rehabilitation and technical support to maximise benefits of cochlear implantation
- ❑ Goal to increase understanding of the requirements of adults who receive CIs from the perspective of the user
- ❑ No previous investigations focused on the user view
- ❑ Share knowledge globally with professionals, policy makers, funders, user and advocacy groups to improve practice and provision

Methodology

- Online survey with both open and closed questions
 - Collect demographic data
 - Document what is in place in terms of rehabilitation and support post-implantation
 - Identify areas of need
- Survey Development
 - Ethical approval obtained from York University
 - Initial version piloted with CI users and revisions made
 - Final version translated into Italian, French, Spanish, German, Portuguese and Czech
- Disseminated via the CIICA network

Who responded to the survey?

- ❑ 1238 respondents agreed to participate in the survey
 - Representing 40 countries
 - Highest numbers of respondents from Germany, Australia, Brazil, United States, United Kingdom, France and New Zealand but good global coverage
- ❑ Ranged in age from 18 to 91 years
 - 10% under 30 years of age
 - Largest percentage (47%) between the ages of 55 and 75
- ❑ Most (94%) reported a bilateral hearing loss
 - Only (37%) used two implants
 - Of 771 using one CI, 55% use a hearing aid in the other ear

How often did you receive fitting, mapping, programming services?

| Year of Implant Use | Most Common Number of Sessions | Range |
|--|--------------------------------|-----------|
| 1 st year | 4 to 6 | 1 to 12+ |
| 2 nd – 5 th year | 2 to 3 | 0 to 12+ |
| After 5 th year | 1 | 0 to 12 + |

How often did you receive rehabilitation or therapy services?

| Year of Implant Use | Most Common Number of Sessions | Range |
|--|--------------------------------|-----------|
| 1 st year | 12+but... | 0 to 12+ |
| 2 nd – 5 th year | 0 | 0 to 12+ |
| After 5 th year | 0 | 0 to 12 + |

But second most common number of sessions was 0!

Did you feel the service you received was sufficient?

| Nature of Service | Yes | No |
|-------------------------------|-----|------------|
| Fitting, Mapping, Programming | 86% | 14% |
| Rehabilitation, Therapy | 68% | 32% |

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% | 23% | 2% | 29% |
| Spare Parts | 48% | 21% | 2% | 36% |
| Replace Processor | 39% | 26% | 1% | 26% |
| Upgrade Processor | 55% | 31% | 1% | 16% |
| Streamers, Accessories | 35% | 16% | 1% | 54% |
| Batteries disposable | 38% | 13% | 2% | 49% |
| Batteries rechargeable | 44% | 20% | 1% | 41% |

Did the pandemic have an impact?

| | | |
|-------------------|-----|---|
| Yes Negatively | 58% | <input type="checkbox"/> Masks and plastic-glass screens <input type="checkbox"/> Reduction of face-to-face services <input type="checkbox"/> Isolation |
| Yes Positively | 20% | <input type="checkbox"/> More awareness of hearing access issues <input type="checkbox"/> More use of technology such as Zoom |
| No impact | 22% | |

Did the pandemic change the services you receive?

| Service | Face to Face Reduced | Online Increased | No Change |
|---------------------|----------------------|------------------|-----------|
| Programming Mapping | 42% | 9% | 55% |
| Repairs | 18% | 8% | 78% |
| Technical Advice | 23% | 11% | 71% |
| Rehabilitation | 29% | 8% | 67% |

30% of respondents did not find the online service satisfactory

**What
were the
most
important
factors in
deciding
to get an
implant?**

**Own decision because of
hearing loss (69%)**

Advice from audiologist (39%)
or surgeon (38%)

Meeting other CI users (34%)

Family influence (20%)

Manufacturer information (11%)

Which services are most important?

As reported in order of importance

Regular Programming, Fitting, Mapping

Funding for Ongoing Support

Access to Repairs

Rehabilitation

Access to Technology Support

Family Support

Peer Group Support

Do you wear your implant?

| All the time | Most of the time | Some of the time | Never |
|--------------|------------------|------------------|--------------|
| 78% | 20% | 2% | <1% (n=6) |

What is your overall satisfaction with your implant?

| Very Satisfied | Satisfied | Not Satisfied |
|----------------|-----------|---------------|
| 72% | 24% | 4% |

What is the take home message?

“I am very satisfied, however it is not perfect - so I wasn't sure how to answer.” (from a CI user)

Overall satisfied – **but** it's complicated... we need to look further ...

- ❑ Great variation in provision in programming and rehabilitation - need to look by country
- ❑ More dissatisfaction with rehabilitation than programming
- ❑ Lifelong funding vital - considerable amount of personal funding particularly for spares and repairs
- ❑ Users made their own decisions - so we need to ensure they have the right information to make informed choices

Next Steps

- ❑ Further work analysing sections on technical provision and funding
- ❑ Analysis of the qualitative data (open survey questions) which will give us the real picture!
- ❑ Further analysis of the quantitative data to investigate impact of global region and other demographic factors
- ❑ Share findings on the CIICA website with our network
- ❑ Produce a report for CIICA members to use in advocacy work to influence policy and provision
- ❑ www.ciicanet.org

