



Connie Mayer

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- Connie worked as a teacher of the deaf for more than twenty years.
- She is currently working on research on literacy outcomes in deaf children, and is leading CIICA's research into adult services after CI.

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?

- ❑ 1082 respondents participated 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
 - Majority (63%) used one implant
 - 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%

**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...

- ❑ 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 looking at the technical provision and funding
- ❑ Analysis of the qualitative data (open survey questions)
- ❑ Further analysis of the quantitative data to investigate impact of global region and other demographic factors
- ❑ Post findings on the CIICA website
- ❑ Produce a report for advocacy work to influence policy and provision for CIICA members.