COCHLEAR IMPLANT SERVICES MATTER

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

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

1. The issue explored

The goal of this consultation was to explore the services that adults experience following cochlear implantation (CI) and their satisfaction with CI services, and then to share this knowledge with professionals, policy makers, funders, and user and advocacy groups globally, to improve practice and provision of services.

2. The Context

Hearing loss is a growing and major health challenge globally with more than 1.5 billion people living with some form of disabling hearing loss. This is projected to rise to 1.9 billion by 2030 and to 2.5 billion by 2050; one in six currently live with hearing loss (WHO, 2021). Hearing loss in adults has a massive, often unrecognised impact on communication, social, mental and physical well-being, and is now the highest cause of Years Lived with Disability (YLD) over the age of 70 (Lancet, 2017; WHO, 2021).

In addition to the personal impact of hearing loss, unaddressed hearing loss has a significant economic impact on both individual and society, with a global financial burden of over 980 billion US dollars (WHO, 2021). Not addressing hearing loss has very significant costs to society, associated with additional health and social care costs (Shield, 2019; Huddle et al., 2017; O'Neil et al., 2016; Lamb et al., 2015; Archbold et al., 2015).

Cochlear implantation provides useful hearing to those with little benefit from hearing aids via surgically implanted devices that require the recipient to wear an external processor which needs individual programming. Cochlear implantation has been shown to be effective and cost-effective (Archbold et al.,2015; Wilson et al., 2017; Mosnier et al., 2015; Mertens et al., 2020; Neve et al., 2021; O'Neill et al., 2016; WHO, 2021). WHO (2021) commented "Cochlear implant is one of the most successful of all neural prostheses developed to date." (P100).

However, in spite of its proven effectiveness and cost-effectiveness, only 5-10% of people who could potentially benefit receive cochlear implants (Sorkin et al., 2016; Vickers et al., 2016). WHO (2021) also commented on the variability of availability of CI even in high income countries. While consensus guidelines for adults have been published, (Buchman et al., 2020), little attention has been given to the ongoing services required following implant surgery in adults. This area was given priority by Foundation Members of the Cochlear Implant International Community of Action (CIICA, 2021) and this global consultation explored this issue from the perspective of CI users.

3. The Process

The consultation investigated the experiences of adult CI users following implantation. Ethical approval was obtained from York University, Toronto (Ethics Approval Certificate e2021-405). The online survey included both open and closed questions, in order to obtain both quantitative and qualitative data. Such an approach enables the researchers to explore issues not thought of at the outset, to determine emergent issues and to provide deeper insights into those issues grounded in the data (Silverman, 2020; Glaser and Strauss, 1967). The survey was developed with a group of deaf and deafened CI users (N=10) of different ages, backgrounds and geography, and revised following comments on clarity, focus and accessibility, considering the range of terminology used in different countries. User groups were involved in the development of the survey at all stages, and the survey (appendix A) was translated into Spanish, French, Italian, German, Portuguese and Czech. It was disseminated, using the Survey Monkey platform, via the CIICA Network (52 countries, and over 40 organisations). All responses to the open questions were translated into English by native speakers familiar with the context. These responses were then reviewed and analysed independently by two qualitative researchers experienced in this area for the emergent themes, then cross checked for agreement. The quantitative and qualitative responses are combined in this report.

4. Views from the consultation from both interview and survey

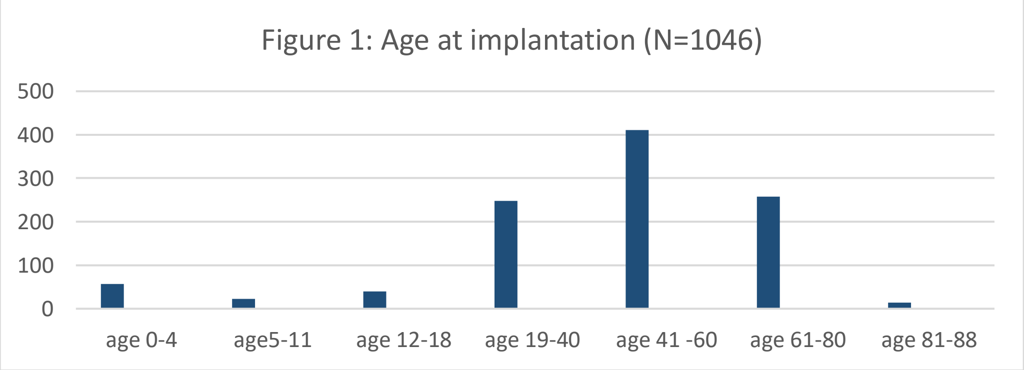
The survey received a large global response, and together with the quantitative data, many open-ended comments were provided. We first describe the respondents, then go on to present the data obtained together with the open responses, illustrating the emerging issues for CI users. The N for each part of the data is given, and varies from question to question. Where anonymous quotations are given, the identifier is country followed by age at CI. Although country is given for interest and identification, we cannot draw country conclusions because of the diversity of response rates, and lack of country-specific data on CI.

Respondents:

There were 1076 respondents residing in 40 countries who completed survey. The largest number of responses came from Germany (n=192; 18%), Australia (n=170; 16%), Brazil (n=132; 12%), United States (n=107; 9%), United Kingdom (n=87; 8%), France (n=73; 7%) and New Zealand (n=55; 5%). There was wide global coverage and the full list of countries is shown in Appendix B; however, it is recognised that this is not a representative sample in each country, nor do the countries of respondents represent the global distribution of Ci practice.

Respondents ranged from 18 to 91 years of age, with 10% aged 18–30 (n=111), and the largest percentage between the ages of 55 and 75 (47%) (n=497).

With regard to age at implantation, Figure 1 shows the spread, with the largest percentage between 41 and 60 years of age at implantation: the youngest was implanted in the first year of life, and the oldest was 88 at the implantation. 113 respondents were implanted under the age of 18, and of these 24% were implanted at 2 and under, 40% between the ages of 3 and 10, and 36% between the ages of 11 and 18.



Most of the respondents (937, 94%) reported a bilateral hearing loss with 60 (37%) using two implants (bilateral implantation). Of 771 using one CI, 55% (421) reported using a hearing aid in the other ear.

Figure 2 illustrates how often they wore their implants showing a high level of CI use:

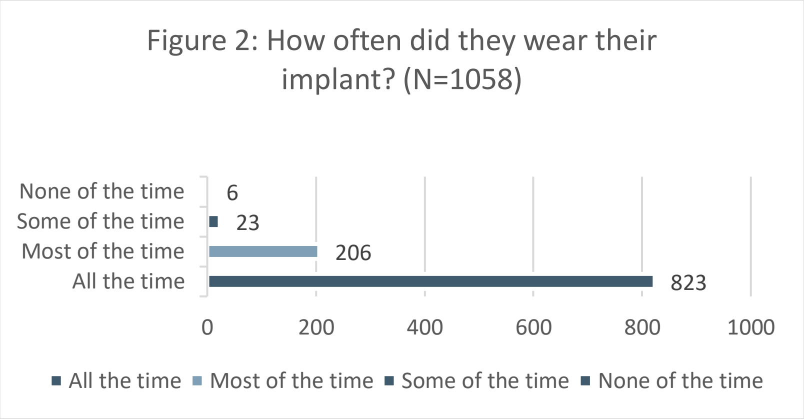
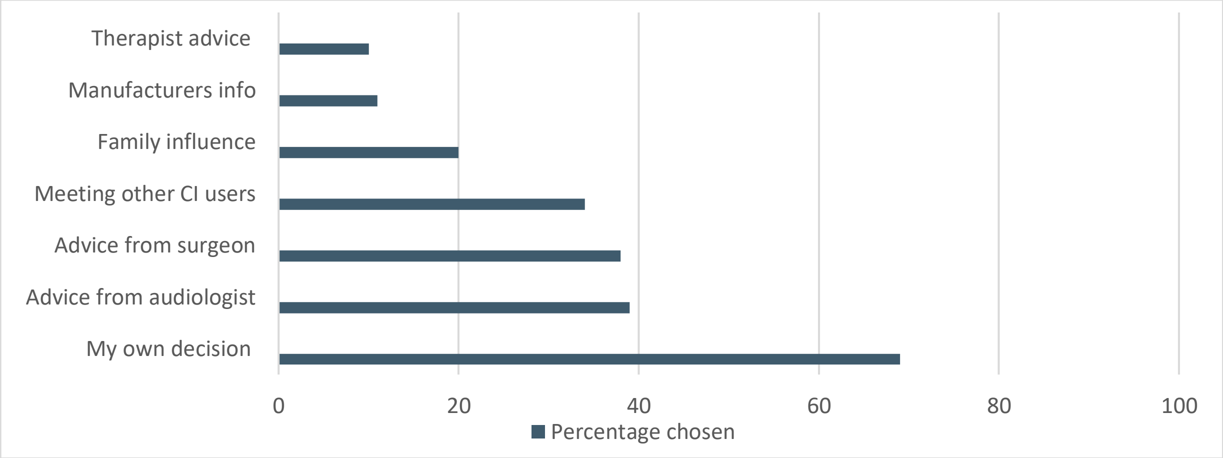


Figure 2: How often did they wear their implant? (N=1058)

5. Decision making

Cochlear implantation involves the individual or their guardian making a decision about the implantation of a technical device into their body which will require lifelong support, may need replacement, and involves a fundamental change in communication and self-perception. When asked the most significant factor(s) in making the decision to have an implant, the most commonly chosen (623, 79%) was “my own decision because of hearing loss” followed by advice from an audiologist (356, 40%) or surgeon (340,38%). Other reasons included meeting other CI users (303, 34%), family influence (180,20%), manufacturers’ information (100,11%) and therapists’ information (87, 10%). Respondents could choose more than one option.

Figure 3: The most significant factor in decision making. (N=900; respondents could choose more than one factor)



Analysing the 132 open ended responses about decision making, 64 respondents gave examples of it being their own decision because of their hearing loss:

> *Because of the isolation, there was no other option for me as my family are all hearing. (Germany,* Age at CI, *41)*

> *I could no longer live without hearing. This was my only way to continue living. (France, Age at CI, 45)*

Of these open-ended responses, 19 mentioned the importance of meeting one or more CI users, sometimes through a CI Association:

> *I encountered a recipient at the theatre where I heard little of the dialogue whilst he said he’d heard it all. He gave me the contact for his surgeon. (Australia, 80)*

> *Another CI user. Laid off work 2017. Struggled in network Groups and lost confidence since my environment changed and no longer had co-workers who accommodated my loss. (USA, 68)*

Others mentioned that they wanted to improve their opportunities, and that hearing loss had negatively impacted their quality of life and brought depression. Other influences mentioned were advice from audiologists, surgeons and family members as well as the wish to keep their job and to hear their family members.

Some commented on the need for time to make a decision, and to receive unbiased information and ask questions:

> *I made time to research and get second opinions. The second opinion was not always welcome by the other professionals but it helped me. (Australia, 60)*
>
> *I wish I had asked more questions (USA,80)*
>
> *I wasn't made aware of possible side effects. (Australia, 18)*

6. Services received after cochlear implantation

Cochlear implantation is a process of which the assessment and surgical procedure are only a start. They are followed by fitting/programming/mapping the external processor and rehabilitation sessions to adjust to listening in communication. This section addresses post-implant CI services: fitting/programming/mapping sessions, rehabilitation sessions, technical support and additional services.

Fitting of the external processor and rehabilitation

Respondents were asked separately about the frequency of fitting/programming/mapping sessions and about rehabilitation/therapy sessions. For ease, the terms fitting and rehabilitation will be used. Respondents were asked about three time periods: the first year after implantation, 2–5 years after implantation and over five years after implantation. (Table 1). Thinking about the number of fitting and rehabilitation sessions, the six choices were 0, 1, 2–3, 4–6, 7–12 and 12+ sessions annually.

Table 1. Numbers of annual fitting and rehabilitation sessions after CI.

Years of implant use	**Most common number of annual fitting/mapping/programming sessions**	**Range**
1st Year	4–6	1–12+
2nd-5th year	2–3	0–12+
After 5th year	1	0–12+
Years of implant use	**Most common number of rehabilitation/therapy sessions provided per year**	**Range**
1st Year	12+	0–12+
2nd-5th year	0	0–12+
After 5th year	0	0–12+

Looking at the first year after CI, the range of fitting sessions provided was 1-12+ and 27% reported no rehabilitation session. While 7% reported over 12 fitting sessions and 16% reported over 12 rehabilitation sessions. The most common responses were 4-6 fitting sessions and 12+ rehabilitation sessions**. However, the second most common response for rehabilitation sessions was zero, indicating the wide variation in services**.

In the period 2–5 years after implantation, 7% reported having no fitting session and 54% no rehabilitation session. The most common number of fitting sessions was 2–3, and the most common number of rehabilitation appointments was zero in this time period.

After the fifth year of implantation, 18% reported no fitting and 70% reported no rehabilitation session. Variations were observed both between and within countries.

When asked specifically whether their services were sufficient, 86% of the 994 who answered the question considered the service received for fitting/mapping and programming sessions were sufficient whereas with regard to rehabilitation, only 68% felt the services were sufficient. On the other hand, some respondents reported needing no rehabilitation and that they had adapted quickly.

However, 32% reported that rehabilitation services were not sufficient. The open responses illustrated this difference:

> *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)*

The need to obtain one's own services arose spontaneously in the open-ended responses:

> *Think initial implant training is lacking across all areas. They leave you somewhat abandoned. (Spain, 39)*
>
> *I was never offered rehabilitation of any kind and created my own. My success with my CI is my own doing, but it would have been nice to have some support. (USA, 22)*

Technical support available

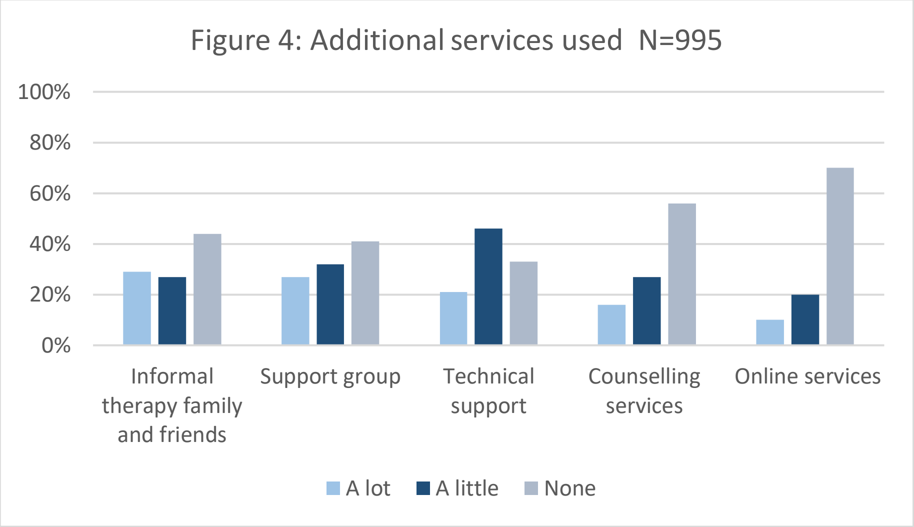
With regard to technical support after CI, Table 2 shows the responses in detail:

Table 2: Technology support and payment

N	Issue	Response
988	Do you know where to go if your processor breaks down?	96% yes, 4% no
988	Quick repairs?	46% yes, 10% no, 44% n/a
865	Spare processor provided in case of breakdown?	74% yes, 26% no
971	Spare parts?	63% had batteries and cables, 11% no spare parts
862	Replacement processor provided in case of irreparable damage?	58% yes, 11% no, 31% don't know
862	Pay for replacement personally?	38% no, 12% pay in part, 13% pay in full
966	Regular upgrades?	53% yes, 21% no, 26% don't know

Additional services used

While rehabilitation services were often limited, respondents were asked about other services or support they used to support their CI. They could choose more than one option from a choice of informal therapy from family and friends, peer support group, technical advice sessions, counselling session, and online/remote services. Of the 995 respondents, there was little in the way of additional services. The most frequent support received was informal therapy from family and friends and from support groups (Figure 4).



There were positive comments about inpatient rehabilitation, which was unusual provision, except in Germany:

> *The best thing that helped me was a 5-week inpatient rehab 2 years after the first implantation. (Germany, 46)*

The impact of COVID on services

The impact of the COVID-19 pandemic on the benefit respondents received from their implant was considered negative by 58% of the 913 respondents due to the wearing of masks, the reduction of face-to-face services, more use of online services, and lockdowns leading to isolation. Only 20% considered it to have had a positive impact: people were more aware of the impact of hearing loss, and the importance of lip-reading and had greater confidence online. Free responses commented on the interruption to services, particularly for those recently implanted.

7. Funding

Having considered the services received and sought, what about funding these? Funding was a major issue to emerge from the survey. In addition to the specific question about funding it emerged spontaneously in all questions as an issue. Cochlear implantation is a process which requires funding of various elements: assessment and the implantation itself, ongoing fitting of the device, rehabilitation and technical support and parts.

Table 3 illustrates the responses from the funding choices of Public/Government Funding, Private Health insurance, Charitable/NGO funding, or Personal Funding for differing parts of the CI process. Respondents could select more than one choice, as funding could come from more than one source. Table 3 illustrates the fragmented funding, with differing sources providing funding for differing parts of the process.

Table 3: The funders of the various parts of the service by percentage

Service	**Public/ Government**	**Private Health**	**Charity/ NGO**	**Other**	**Personal**	**Total respondents**
1st implant	67%	35%	2%	5%	**9%**	966
2nd implant	48%	40%	1%	9%	**14%**	494
Mapping/Fitting	67%	24%	3%	5%	**10%**	901
Rehabilitation	63%	20%	3%	8%	**16%**	763
Repairs	50%	23%	2%	9%	**29%**	895
Spare parts	48%	21%	2%	8%	**36%**	885
Replacement processor	39%	26%	1%	18%	**26%**	793
Upgrade processor	55%	31%	1%	8%	**16%**	821
Streamers and other accessories	35%	16%	1%	8%	**54%**	812
Batteries, disposable	38%	13%	2%	6%	**49%**	782
Batteries, rechargeable	44%	20%	1%	6%	**41%**	782

While most implants are funded initially by public or government funding, including state health insurance, significant percentages are covered by private health insurance. Looking at further detail, less of the ongoing costs are covered by private health insurance. This includes the ongoing services needed for mapping/fitting and rehabilitation, or the technology support costs such as repairs, spares, replacements, accessories and batteries. The costs which are covered by CI users are highlighted in the table and indicate the percentage of individuals who pay themselves for spare parts, accessories and batteries, which are vital to the use of the implant system. It illustrates the amount of personal funding that is expected in many countries irrespective of the user's income level.

The 190 open-ended responses reveal the financial impact on individuals and families, with 23% commenting on the need to pay personally for accessories and replacements. The challenge of reliance on personal funding also arose in responses to other questions, and comments on the expensiveness of CI and the spare parts or accessories were common.

> *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).*
>
> *Once implanted, especially at young ages, there are lifelong costs associated with mapping, repairs or replacing parts and the event that the processor is damaged or lost and since being implanted so young it's very possible there could be a need for re-implantation if the device fails after 30-40 years or longer. (USA,50)*

Some comments show how lack of funding may lead to not having regular checks or even to non-use or the inability to replace a processor, or a repair:

> *It is difficult to have a productive mapping session when they are so seldom and expensive out of pocket. I have postponed what should be an annual appointment due to cost and having to jump through insurance hoops to get in the door every time (USA, 22)*
>
> *In NZ I have to pay for the program checks, which is a major disincentive now I'm retired*
> *(New Zealand, 68)*

Difficulty exchanging [the CI] when it was obsolete, and family members did not have the income to buy [a new one]. (Brazil, 1)

Speech processor broke after 20 years – and really difficult to find another one, at the end I got one second hand … but I cannot pay for programming and speech therapy. (Mexico, 6).

Because it broke and I don't have another device - I was and still am very sad. (Brazil,25)

Suggestions were made about funding options to provide sustainable services:

They should be fully funded by the public administration. (Spain, 28).

You could have a monthly or annual plan, like a health plan, to guarantee the condition of the processor or purchase a new processor if you need it, mapping every 6 months, speech therapist service 4 sessions a year (apart from surgeries, medical expenses). (Brazil, 17).

I'd like a type of financing that I could pay monthly to replace my parts (Brazil, 4).

Suggestions were also made about guidelines which could support funding:

Global guidelines for lifelong aftercare that cannot be disputed at will by health insurance. (Germany, 40).

8. Users' reports of satisfaction

Users were asked about their satisfaction with both cochlear implants and with the services they received. Firstly, their satisfaction with the cochlear implant technology is reported.

8.1 Satisfaction with their cochlear implant technology

Asked about overall satisfaction with their implants, there were high levels of satisfaction, with 663 (72%) of respondents being very satisfied, 217 (24%) satisfied and 38 (4%) not satisfied. (Figure 5): N=918)

There were 445 free responses to this question about satisfaction with implants; the largest number received for a question. The majority described positive experiences with comments such as:

Super satisfied: my CI is the best decision I made in my life (Brazil, 32)

It was the best thing I ever did. (UK, 58)

Going back to listening is priceless – my life has been completely changed for the better. (Brazil,45).

Incredible technology: allows me to be in the real word. (Australia, 48)

I changed my life as a 64 year old adult (Argentina, 64).

> *I am amazed how much I can hear. (Germany, 55).*
>
> *I live again! I have an almost normal life. (France, 50).*

Others commented that CI made it possible to participate in professional, social and private daily life, and to lead a “normal” life:

> *It has enabled me to return to full time work after motherhood and perform at a higher level than when I was struggling to follow speech. (Australia, 49)*

Other comments include being able to listen to and play music, to listen to podcasts, to join online meetings, to make phone calls and thereby enjoy more confidence and greater independence.

118 of the open ended responses conveyed some challenging experiences, giving examples of lack of benefit, lack of knowledge and information when making the decision to have CI, challenges in noise and in groups, and the impact of technical failure. Comments indicated it had taken a long time for some to adapt to CI (mentioning age, headaches, vertigo, need for effort, tinnitus):

> *I still can’t get used to the noises. (Brazil, 43)*
>
> *Noisy areas are still difficult. (Australia, 69)*
>
> *Impossible for me to be in crowds and restaurants. (France, 45)*
>
> *It resulted in little improvement in hearing. (Australia, 22)*

8.2 Satisfaction with CI services

Satisfaction with the CI services received was slightly lower than satisfaction with CI: overall 511 (56%) of those 912 respondents to the question were very satisfied with the services received, 365 (40%) satisfied, (N=912). However, those not satisfied with their CI were not likely to be satisfied with their services. 18% of respondents indicated that they would have liked more support, and more comprehensive and frequent services. Figure 6 illustrates the high satisfaction rates:

There were 262 free responses to the question as to satisfaction with the services received, largely indicating high levels of satisfaction, with 99 (38%) making comments which indicated that they were provided with great support.

Comments on outstanding service described real partnerships:

> *(At my hearing centre) I find love, attention, and dedication from a whole team of competent professionals who complement each other. (Brazil,43)*
>
> *Very satisfied with the support from the hospital in terms of programming, and rehab, but really miss not having peer support groups. (Ireland, 50)*

> *The support I'm receiving is wonderful and now I feel that life is much better and I have a future to look forward to as I grow old that someone cares. (Australia, 57)*
>
> *I hit the jackpot with my audi and doc – they rock! (USA,59)*
>
> *I feel well supported. Much more so than in all the years I have used hearing aids. I actually feel listened to and significant. (NZ,64)*

However, 55% of the free responses also indicated that there was a need for more funding, staffing, time and resources, and commented that they needed to source their own support and advocate for themselves. Manufacturers' teams were valued where available.

8.3 CI Services matter: Satisfaction with CI is linked with satisfaction with services

The evidence from respondents indicates that satisfaction with CI was linked to satisfaction with the services received: those very satisfied with their CI were more likely to consider the CI services sufficient and to be satisfied with their services. Looking at the reported satisfaction and non-satisfaction rates with CI and with services with regard to other variables, these are the issues which emerge:

- **Full time Use:** Those who wear their implants full time are more likely to be satisfied with CI.
- **Age at CI:** Those who were implanted as children and those implanted over 80 were the most satisfied with their CI and their services.
- **Public Funding**: Those with public funding were more likely to be satisfied with CI services than those funding personally or through insurance.
- **Two CI:** Those with bilateral cochlear implants were more likely to be satisfied with CI and services.
- **Regular upgrades**: Those with regular upgrades were more likely to be satisfied with CI and services.
- **Number of fitting sessions:** Satisfaction with both CI and with fitting services was linked to reporting 4-6 fitting sessions in the first year.
- **Lack of fitting sessions**: Those reporting no fitting services after the first year are more likely to be dissatisfied with CI and services.
- **Number of rehabilitation sessions:** Those who were very satisfied with their CI tended to report 12+ rehabilitation sessions in the first year.
- **Lack of rehabilitation sessions:** Those who were not satisfied with CI tended to report no rehabilitation sessions in the first year and in the following years.
- **Technical support:** Those satisfied with both CI and CI services were more likely to know where to go for help, to have spare parts, to have replacement processors, to have quick repairs and to have regular upgrades.
- **Informal therapy:** Those who were satisfied with services were more likely to have informal therapy with family and friends, peer support/family group, CI group, counselling sessions and online sessions than those who were dissatisfied with their services.
- **Self-initiated support:** Those who were very satisfied with CI services were more likely to have self-initiated their own support and done self-guided training.

9. Lifelong services: what do CI users consider is needed and why?

Throughout the responses there was a theme of reliance on implants for everyday communication and the need for lifelong services was highlighted. When asked specifically about the importance of lifelong services, of the 921 respondents, 856 (93%) thought they were very important, 56 (6%) important and only 9 (1%) not important.

The majority of the 341 free responses to this question illustrated the reasons for their views:

> *I will have my CI s all my life. I should have support for them all my life. (Germany, 33).*
>
> *Because all life we must hear. (Spain, 28).*
>
> *Without lifetime services, how to solve technical problems repairs etc? (Brazil, 77)*
>
> *Once in place the CI is a daily necessity so it is imperative that everything works well at all times. (France, 52)*
>
> *It's a medical device in an ever-changing world of medical growth- cochlear implants are continuously improving and, just like computers, the devices must be maintained, upgraded and repaired. It's a lifelong commitment and lifelong insurance should be connected to it. Brazil, 45).*
>
> *VERY VERY VERY important – the implant must be well-looked after throughout its life. (Germany, 41)*

When asked the most important part of CI services to support lifelong benefit, regular fitting, closely followed by access to repairs, rehabilitation and funding for these were considered most important.

When asked for final comments, once more lifelong services and funding emerged spontaneously as a major issue (N=341), including for those implanted as children:

> *Implanted people need continuous, lifelong medical coverage for their device and all things related. ….. 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)*

The recognition of their dependency on CI for daily communication led to many comments highlighting the necessity of lifelong support:

> *I need reassurance that my CI will work and be supported right up to the day I die. So, I need batteries, coils, cables, filters, chargers, upgrades etc., and also need to be convinced that my CI will be managed for me if I end up in a home for old people. (Finland, 45)*

The respondents showed insights into the challenges for the provision of lifelong services for them. They were aware that while the numbers who require these services grow, increasing the demand, there are already issues with insufficient staffing, with distances to specialist CI centres, in addition to the major challenge of finance.

9.1 Technical support and management

There were comments throughout about the challenges of managing the equipment in everyday life, and the need for training and support and timely appointments when something goes wrong:

> *I consider necessary the sessions of technical advice and advice that I have not received. (Spain, 50)*
>
> *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)*

> *Appointments for technical advice? There is no such offer here. But I would like to take advantage of it. (Germany, 48)*
>
> *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)*

Some mentioned the challenges of staying up to date with the technology and innovation:

> *More information about periodic reviews and new technologies. (Brazil,77)*

There was a consensus that at least an annual review was necessary, as deteriorating or intermittent functioning may not be noticed. Several mentioned the inclusion of an ENT check:

> *A check of the correct functioning of the CI, a correct adjustment of potential, any updates, at least once a year, remain essential for me. (Italy, 66)*
>
> *It's an implant in the body that needs to be checked regularly. (Germany, 50)*
>
> *After 10th year there aren't any follow up visits or check by ENT doctor. I consider these necessary because one is still wearing an internal part that can cause real problems, (Spain, 42)*

More flexible management, including being accessible when needed and supporting the ability to solve one's own problems, was highlighted.

In order to provide these services, there were many comments that locally available services were important:

> *Being more accessible when it comes to a problem with the processor (Spain, 52)*
>
> *Greater presence (of services) throughout the territory (France, 48)*
>
> *It would be very good if there were CI acousticians all over the country. (Germany, 55)*

9.2 Lifelong Rehabilitation Services: what should they include?

A third of respondents considered that rehabilitation services were insufficient and open-ended responses conveyed insights into how they should be delivered and what they should include. There were comparatively few requests for listening training, but rather more for technology support, telephone training, assistive devices, and that the services should be individualised – everyone is different.

Personalised services

The lack of personalised services emerged spontaneously as an issue:

> *There have been times when the audiologist did not believe or respond to issues I had/have.… (Australia, 51)*
>
> *I'm satisfied but I'd like to have a more personal approach in the mappings and programming. (Portugal, 26)*
>
> *There is a huge push for audiologists to get CI users to required mapping and not let the CI users choose what may benefit them. It was a terrible hassle to go back and forth if mapping wasn't right. (USA, 3).*

And again, a lack of personalised services in adjustments to CI and providing necessary technical information:

> *Difficult when you have a bad Mapping/Programming, you have to wait some time for next appointment. It causes a lot of stress. (Australia, 61)*
>
> *I've only had my implant for a year. There's a lot of things I didn't know that I didn't know- for instance all the equipment needed and change of filters etc. (NZ,64)*
>
> *The first adjustments did not go well (no follow up, change of professional every time, no explanation on personal experience (feels)). (France, 40)*

Peer group support was important too:

Peer group support had been influential in decision making and continued to be important after implantation:

> *The most helpful to me have been online groups and Facebook run by fellow recipients of cochlear implants.* (USA, 62)
>
> *Nothing can compare to having the understanding of a clinician or a peer who understands the unique challenges that we CI-users face every day. (Australia, 29)*
>
> *You have to know yourself what you need. If you have contact and peer support with other CI users, you know more what you ask. (Finland, 41)*

Counselling services

Few respondents reported receiving counselling services, and the open-ended responses revealed that this would often have been valued:

> *I feel the first year (2019) I thrived so much with my CI. This past year I struggle with accepting my deafness and the new sounds. (USA, 35)*
>
> *I would have liked counselling services. There is a lot of grieving, exhaustion, disappointment and frustration in this whole journey (of losing hearing, followed by CI). And it is perennial. (Australia, 67)*
>
> *I would have loved if there had been in-house psychological counselling at my hospital/CI Center as well. (Germany, 45).*

10. Discussion

The large response to this global survey on experiences of adult CI services and the numbers of free comments report very high levels of satisfaction with both implant technology and services. While the survey cannot claim to be a representative sample of the global population of adult CI users, there are a number of key issues to consider for planning and delivery of services, and which could improve equity of access to CI and related services and ensure maximum lifelong benefit.

Decision making

Underlying many of the free responses was the important role of personal responsibility, linked with information for decision making. The difference between deciding for and managing an implant involving an irreversible surgery, and the decision about a hearing aid is considerable. The decision-making regarding CI is more challenging (Ng et al., 2016; Rapport et al., 2020; Hubner et al., 2022) and CI users, even satisfied ones, commented on not having been aware of the ongoing technological management required, or the ongoing funding issues. Given the lifelong commitment, and the ethics of implanting a device within the body, the need for clear information is evident (Rapport et al., 2020; Schulz et al., 2022). Schultz et al., (2022) also commented that the patient perspective should be included to ensure that information is transparent and understandable. Hubner et al., (2022) point out the challenges of obtaining and understanding up-to-date complex health and technical information, the conflicts of industry involvement in CI and difficulties in decision making and found that users commented that they wanted more advice and clearer explanations. Looi et al., (2022) in reviewing CI brochures from industry found that those used prior to implantation are often of high educational and reading levels and recommend that they are revised for readability; in this study the users rated the industry information as relatively low in influence. To ensure that thinking about CI is informed, it is vital that non-specialist healthcare professionals are up to date about CI to support timely referrals and informed decisions (Hubner et al., 2022; Bierbaum et al., 2020).

High levels of satisfaction with CI in adults and with CI services

Following CI, there were very high levels of satisfaction with CI itself and its positive impact on lives for this global group of adult users with the impact of CI in terms of increased confidence and ability to advocate for oneself. Hubner et al., (2022) and Ng et al., (2016), with others, also reported increased confidence after CI leading to increased autonomy; this autonomy is evident in the open responses to our survey. These high satisfaction rates reflect reliance on CI for everyday communication and functioning. While satisfaction was very high overall there were degrees of satisfaction: the greatest satisfaction was with the impact of the device itself, followed by satisfaction with fitting services, and followed by satisfaction with rehabilitation services. This lower satisfaction rate could be related to the reported wide variation in provision.

Wide variation in services provided

WHO notes that there is extremely limited research and data on the factors limiting CI use, and that "high costs and shortages of trained workforce and rehabilitation services, have resulted in their restricted accessibility to countries other than those in high-income groups – with considerable variation even within these" (WHO, 2021, p.179). In this study there was huge variation in the numbers of appointments reported both within and across countries. The range of fitting sessions per year after the first year of use was reported to be from 1 to over 12, and the range of rehabilitation sessions from 0 to over 12 throughout, including the first year. However, it doesn't appear in this study that the "more the better" necessarily translates to high levels of satisfaction: in the first year, the highest satisfaction levels were in those who had between 4–6 fitting sessions. Low satisfaction was linked to having no fitting services or rehabilitation services, even after five years. There was an awareness that regular monitoring was necessary for an implanted device on which the user relies for everyday communication. There was a consensus that at least an annual check was necessary, and that access to emergency cover was essential to maintain communication in everyday life, including employment. The production of guidelines such as the Living Guidelines (CIICA, 2023) provides some support for advocacy by CI users for less variation in services.

Lack of rehabilitation services for adults: self-initiating one's own

While variation in frequency of services was considerable, it was particularly so for rehabilitation services. Rehabilitation was reported as not being considered important in adult services compared with children. It may be that it is more important for adults: children have parents and teachers to provide daily rehabilitation and support in real life. Adults may live alone and have no further support or input. WHO (2021) recommends that CI should not go ahead without the necessary rehabilitation infrastructure in place.

There was greater satisfaction amongst those who self-initiated their own rehabilitation, had informal rehabilitation with family and friends, in those who sought peer groups and belonged to CI organisations. Volunteer organisations and NGO's, are clearly providing considerable support and information; this is valued, but there is potential for misinformation unless managed well and in collaboration with professionals. How high quality peer group support can be provided and funded is a major issue. Patient activation, the knowledge, skills and confidence that people have to manage their own health and care, has been shown to be closely linked with clinical outcomes and higher reports of the patient's experience (Hibbard & Gilburt, 2014), as was the case here.

In the UK, the British Cochlear Implant Group have revised their Quality Standards (Cullington et al., 2023) and offer multi-professional guidelines. However, as the Living Guidelines project found (CIICA, 2023), while there are evidence based guidelines for surgery and programming the systems, there are none for the ongoing lifelong care to facilitate benefit in everyday life or for rehabilitation. Ray et al., (2021) also found no research reported on the value of rehabilitation or what it should consist of and they argue for the role of speech and language pathologists in the CI team. This is included in the global Living Guidelines (CIICA, 2023). Psychological support was rarely available and would have been valued, particularly by those who cho~~o~~se to have CI following hearing loss.

Challenges of managing the technology

In spite of, or perhaps because of, the high levels of satisfaction with their implants, concern was raised about their personal management of their technology and the frustrations with it in everyday life, and the management and funding of repairs and accessories. There was an element of anxiety in many of the free responses, reflecting their reliance on functioning CI systems for everyday life. It was reported by 11% that they had no spares at all with implications for everyday management.

This group reported wanting and needing more support in managing the technology in daily life: particularly concerns in older people who found the technology difficult to manage. Satisfaction levels in the older age range were lower and this group was mentioned to be more likely to need hands-on training with the technology; they may also have other physical difficulties – sight, dexterity – which makes management of the technology more difficult.

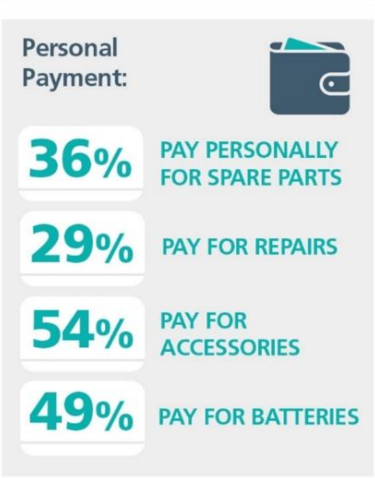
As people have become more confident with online services as a result of the COVID-19 pandemic, this can be one time-effective way forward, but for many "hands on" was required. This need not necessarily be provided at the CI centre, but non-specialists or user groups could provide some of the technical support required, when staffing levels are challenging.

Lifelong services

A major issue arising in the free responses was an awareness of the need for lifelong services. The very high levels of satisfaction with implants means that users are dependent on this technology for everyday communication and functioning, and this is lifelong. Schultz et al., (2022) commented that rehabilitation and long term maintenance should be included as part of the process, and that uncertainty about health care policies and provision can cause anxiety. The words dependency and dependent were common in the free responses, reflecting the vulnerability of this group. This confers a huge responsibility for those providing CI services. There are estimated to be one million users of CI (Zeng, 2023) of whom 65% are estimated to be adults (personal communication with industry).

The respondents were clearly aware of these growing demands on CI services and commented on the shortage of specialized staff and were also aware of the impact of the pandemic on services. Much thought has been given to new ways of delivering CI services, with industry supplying online options, making the delivery of services at home and in the community rather than in specialist centres possible (Athalye et al, 2016).

Funding



Personal Payment:

36% PAY PERSONALLY FOR SPARE PARTS

29% PAY FOR REPAIRS

54% PAY FOR ACCESSORIES

49% PAY FOR BATTERIES

As has been demonstrated, CI services consist of a range of services, not always integrated, and often provided by different providers with different funding. Coordinating these services and their funding is complex, but sustainability is essential. The biggest issue to emerge was concern about ongoing funding to ensure security of lifelong device use. In free answers to every question, the issue of funding emerged spontaneously. Several other studies have also documented this issue (Schultz et al, 2022). Different areas of the CI process are funded differently and the services are fragmented. The lack of ongoing funding led in a few cases to lack of CI use, without funding for repairs or replacements. The personal implication of lack of funding are immense to the individual, but lack of long-term investment for CI also has implications for society. This group of respondents suggested other ways of ongoing funding to which they would be willing to contribute: ongoing personal insurance and annual maintenance contracts for example. In a study by Ng et al (2016) adults in the UK valued their implants at over £150 per month, a considerable sum.

As cochlear implantation has been shown to be effective and cost-effective for individuals and society, the funding of lifelong services is vital to ensure the maximum return on investment for individual and society.

Health literacy in CI services

The issue of health literacy, having the understanding and confidence to make decisions about one's health care, was underlying many responses in this survey of CI users. The global experience of the impact of the COVID-19 pandemic on health systems has made the public more experienced in understanding and questioning public health issues and data, and to wish to participate in public health decisions. This was also true of these respondents.

As Hubner et al., (2020) note in their study for users to benefit fully from their implants requires a number of skills. This includes understanding and processing complex information to be able to make informed decisions on health care (Nutbeam, 2008), navigating and managing interactions with a number of health professionals, while undergoing a radical change in their lives. It also involves the ability to process health-related technical information and to successfully operate technical devices (Hubner et al., 2022). Schultz et al., (2023) recommended that technology related health literacy should be included as a dimension of the topic.

This level of agency implies that health literacy is not something that can simply be assumed but has to be supported and developed in a real relationship between users and professionals. Further, as our research suggests, we need to move more towards models of co-production and co-creation of services where patients are not the passive recipients of services defined elsewhere but help create their own. This can only happen if supported through a conscious partnership on both sides (Muscat et al., 2022). In this research, users were involved in the design of the survey, not only in piloting it as is common. The aim of this was to make the survey relevant to users and to be informed by the changes they wanted to see as recommended by Dawes et al., (2022).

Health systems need to consider how patients are supported to gain knowledge of hearing loss and to be able to have the information and confidence to use this in working with clinicians and professionals to ensure that their needs are met. Currently the support networks and advice often come from other users, the internet and self-help groups. More thought needs to be given to how up to date information and support can be provided through choosing an implant, the process of fitting and ensuring that the right aftercare is in place. For this to happen and to be funded lifelong, CI must be part of Ear and Hearing Care services in healthcare systems which recognise the agency of the user and patient.

11. Recommendations

The clear messages our respondents gave led to these recommendations for CI services:

- 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.
- Access to CI needs to include access to lifelong services, particularly technology management.
- Lifelong Adult 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, ~~I~~include at least one appointment annually to monitor progress and check device functioning.
    - Include quick and ready access to technology support when required.
    - Provide spare parts such as processors, cables and coils to ensure continuity of functioning.
    - Include regular processor upgrades.
    - Provide access to bilateral cochlear implants where appropriate.
    - Provide access to appropriate peer group support and counselling services.
    - Be person-centred, focussing on collaborative services with CI user input.
    - 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. So that all can benefit, funding must not depend solely on patient contributions.

12. Conclusion

Access to communication in daily life is included in Article 9 of the Convention on the Rights of Persons with Disabilities which states “parties shall take appropriate measures to ensure to persons with disabilities access on an equal basis with others, to the physical environment, to transportation, to information and communications..." (UN, CPRD Accessed at Convention on the Rights of Persons with Disabilities (CRPD) | Division for Inclusive Social Development (DISD) (un.org))

Respondents to this consultation confirmed the life-changing impact of cochlear implantation in adulthood and its role in everyday communication, providing access to family life, education, employment and social life. This effectiveness leads to dependency on the optimal functioning and use of the technology in everyday life, and this in turn leads to the demand for the necessary, effective services to ensure this functioning, and the funding and infrastructure to support them. It also requires clinicians and professionals to ensure that patients are involved fully in the design and delivery of services and that patient literacy is supported and patients listened to.

CI services are specialist, multi-professional provision and need to be there for the lifetime of the individual. With the growth in CI services required, whose is the responsibility to ensure their potential is realised and maintained? How can we ensure that this essential, cost-effective provision is included in global ear and hearing services?

As respondents said:

You can save yourself the question: I’ll be dependent on it for the rest of my life. (Germany, 12)

No implant: no sound, no family life, no friends, no job (I am a nurse),no birds, no cat’s purr, no wind in my ears, no sound of waves, no children’s laughter…. Implants= life (France, 27)

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Appendix A: The Survey

Thank you for your interest in this survey!

Consent page

Thank you in advance for taking the time to share your perspectives and help us with this important project.

We are inviting you to participate in a survey investigating the views of adult users of cochlear implants (CIs). We want to learn about your experiences from the time you got your implant(s) and understand more of what you feel is needed to provide the best support in the long term.

This research is the first of its kind, and provides an opportunity to influence the lifelong provision for adult CI users from a global perspective. This project is a partnership between the Cochlear Implant International Community of Action (CIICA) (https://ciicanet.org/) and York University in Toronto, Canada. We believe that findings from this research will inform policy and planning to improve support for lifelong aftercare for adult users of CIs.

The objectives of this survey are to learn more about what is needed to provide the best support to adult users of cochlear implants from the perspective of the users themselves.
You should know that:

- Participation in the survey is completely voluntary.
- The survey is completed entirely online. You will be asked questions about your cochlear implant experience (e.g., number of implants, years of use, services you have received) and also given an opportunity to make suggestions on improving long term support. The survey has 35 questions, but we have made it as straightforward to answer as possible as we really value your time.
- You may skip questions you prefer not to answer.
- You can withdraw at any time by closing the survey.
- We do not foresee any risks or discomfort from your participation in the research and withdrawing from the study or refusal to take part will not affect your relationship with CIICA or York University.

All data is collected anonymously. Your name will not appear in any report or publication of the research. Only de-identified, aggregated information will be reported. Your data will be safely stored on a password-protected computer and only research team members will have access to this information. All data collected from this survey will be destroyed (i.e., files deleted) at end of December 2022.
Confidentiality will be provided to the fullest extent possible by law.

The researchers acknowledge that the host of the online survey (i.e., CIICA) may automatically collect participant data without their knowledge (i.e., IP addresses). Although this information may be provided or made accessible to the researchers, it will not be used or saved without participant's consent on the researchers' system. Because this project employs e-based collection techniques, data may be subject to access by third parties, as a result of various security legislations now in place in many countries, the confidentiality and privacy of data cannot be guaranteed during web-based transmission.

If you have questions about the research in general or about your role in the study, please feel free to contact Dr. Connie Mayer either by telephone (416-736-5971) or by e-mail (cmayer@edu.yorku.ca). This research has received ethics review and approval by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri- Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, Kaneff Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca).

This survey is funded by a grant from Social Sciences and Humanities Research Council of Canada

* 1. Before we begin the survey please can you confirm you have read the above information and agree to participate in this survey?

○ Yes, I have read the invitation and agree to participate in this survey.

○ No, I do not agree to participate in this survey.

Thank you for helping with this survey! Firstly some background questions:

Background information page

2. Which country do you live in?

TEXT

3. Are you a member of any local or international CI organization(s)/association(s)

○ Yes ○
No

If Yes, please give the name of organisations:

TEXT

4. How old are you?

TEXT

5. Do you have a hearing loss in both ears?

TEXT

6. Do you have two implants or one?

TEXT

7. What year did you get your first implant?

TEXT

8. If applicable what year did you get your second implant (in your other ear)?

TEXT

9. If you have one implant, do you wear a hearing aid in the other ear?

TEXT

10. Do you wear your implant:

TEXT

Your Experiences After Implantation

11. In the first year of implantation how many times did you receive the following services?

	0	1	2-3	4-6	7-12	12+
Fitting/Mapping/Programming Sessions	○	✓ ○	○	○	○	○
Rehabilitation/Therapy Sessions (for example: Listening Training, Communication Training)	○	✓ ○	○	○	○	○

12. In the second to fifth years of implantation how many times did you receive the following services per year?

	0	1	2-3	4-6	7-12	12+
Fitting/Mapping/Programming Sessions	○	✓ ○	○	○	○	
Rehabilitation/Therapy Sessions (for example: Listening Training, Communication Training)	○	✓ ○	○	○	○	○

13. After the fifth year of implantation how many times did you receive the following services per year?

	0	1	2-3	4-6	7-12	12+
Fitting/Mapping/Programming Sessions	○	✓ ○	○	○	○	
Rehabilitation/Therapy Sessions (for example: Listening Training, Communication Training)	○	✓ ○	○	○	○	○

14. Did you feel the service you received was sufficient for each of the following?

	Yes	No
Fitting/Mapping/Programming Sessions	✓ ○	○
Rehabilitation/Therapy Sessions (for example: Listening Training, Communication Training)	✓ ○	○

Comments:

TEXT

15. Which organisation provided the services for each of the following?

	Public CI Centre	Charity/NGO	Public Hearing Services	Private Hearing Services	CI Manufacturer	Don't Know	Other
Fitting/Mapping/Programming Sessions	☐	✓ ☐	☐	☐	☐	☐	☐
Rehabilitation/Therapy Sessions (for example: Listening Training, Communication Training)	☐	✓ ☐	☐	☐	☐	☐	☐

If Other (please specify)

TEXT

16. Did you receive or attend any of the following to help you to learn to use your CI?

	Yes, a lot	Yes, a little	No
Informal therapy from ✓	○ ✓	○	○
Peer support/family group	○ ✓	○	○
Technical advice sessions on using accessories/telephone etc.	○ ✓	○	○
Counselling sessions	○ ✓	○	○
Online/Remote services	○ ✓	○	○

Please comment further if you wish:

TEXT

Repairs, replacements and upgrades

17. If your processor breaks down do you know where to go?

○ Yes ○ ✓
No

18. If you have had a processor repaired was it repaired quickly?

○ Yes ○
No ✓
○ Not applicable

19. If you need a repair do you get a spare processor?

○ Yes ○
No ✓

20. Do you have spare parts? Select all that apply

☐ Cables
☐ Magnets ✓
☐ Charger
☐ Batteries

☐ Remote controls Other
☐ No spare parts
☐

Other (please specify)

TEXT

21. If you lose or irreparably damage your processor do you receive a replacement?

○ Yes ○
No ✓
○ Don't know

22. If yes do you have to pay for the replacement?

○ In full
○ Partly ✓
○ Not pay at all Don't
○ know

23. Is your processor regularly upgraded?

○ Yes
○ No ✓
○ Don't know

If yes how often?

TEXT

Funding

24. Please select who funds the following for your CI and services? Tick all that apply

	Public/Government funding	Private Health Insurance	Charitable/NGO funding	Personal funding	Other
First Cochlear Implant	☐ ✓	○	○	○	○
Second Cochlear Implant	☐ ✓	☐	☐	☐	☐
Mapping/Programming	☐ ✓	☐	☐	☐	☐
Rehabilitation	☐ ✓	☐	☐	☐	☐
Repairs	○ ✓	○	○	○	☐
Spare parts	✓				
Replacement processor (damaged or lost)	☐ ✓	○	☐	○	☐
Upgrade processor	✓				
Streamers/accessories	☐ ✓	○	○	○	○
Batteries (disposable)	✓				
Batteries (rechargeable)	☐ ✓	☐	☐	☐	☐

Other (please specify)

TEXT

General Comments

25. Has the pandemic impacted on the benefit you get from your implant?

○ Yes, positively ○

✓ Yes, negatively ○ No

26. If yes please select how?

☐ Mask wearing/Use of plastic-glass screens

☐ Reduction of face to face services Isolation

✓ ☐ because of lockdowns

☐ People being more aware of hearing problems More use of

☐ technology such as Zoom

☐ Other

If other (please specify)

TEXT

27. Has the pandemic changed the services you receive?

	Face to face service reduced		Online service increased	No change
Programming/Mapping	☐	✓	☐	○
Repairs	☐	✓	☐	☐
Technical advice	☐	✓	☐	○
Rehabilitation	☐	✓	☐	☐

Comments welcome:

TEXT

28. Do you find online CI services you have received satisfactory?

○ Yes ○

✓ No

Tell us about your experiences with online services:

TEXT

29. How satisfied are you with your cochlear implant?

○ Very satisfied ○
[✓ Satisfied]
○ Not satisfied

Please explain your answer:

TEXT

30. What were the most significant factors in your decision to have an implant?

☑ Surgeons advice
☑ Meeting one or more CI users
☑ Manufacturers information e.g. website, poster Family
☑ influence

☐ Audiologist's advice
☐ Own decision because of hearing loss Therapist's advice
☐

Other (please specify)

TEXT

31. How important do you think lifelong CI services are?

○ Very Important ○
[✓ Important]
○ Not important

Please explain your answer:

TEXT

32. Overall are you satisfied with the service you have received?

○ Very Satisfied ○
[✓ Satisfied]
○ Not Satisfied

Please explain your answer:

TEXT

33. What is the most important part of CI services to support lifelong benefit? (Please put these in order of importance, 1-7 with 1 being most important)

☐ TEXT
Regular programming/mapping/fitting

☐ TEXT
Rehabilitation

☐ TEXT
Access to repairs

☐ TEXT
Access to technology advice

☐ TEXT
Peer group support

TEXT
☐
Family support

☐ TEXT
Funding for ongoing support

34. Is there anything more you would like to tell us about the lifelong CI services you think you need and what you would like?

TEXT

35. Thank you for completing this survey, we really appreciate it.
If you would like us to send you a copy of the report or be involved in further research, please send us your name and email address below.

Appendix B: Countries of respondents in order of response rate:

Germany
Australia
Brazil
United Kingdom
United States of America
France
Belgium
Spain
Israel
Netherlands
Austria
South Africa
Sweden
Canada
Italy
India
Ireland
Denmark
Finland
Romania
Vietnam
Estonia
Portugal
Mexico
Iceland
Argentina
Czech Republic
Kenya
Slovenia
Norway
Malaysia
Sri Lanka
Azerbaijan
Slovakia
Ecuador
Luxembourg
El Salvador
Georgia
Gambia
Philippines

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