

# Young Adults with CI Matter

## IFOS –ASEAN –ORL-HNS INTERNATIONAL – VSO

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**Steering Committee, World Hearing Forum, WHO**



# 1 million implanted globally (Zeng,2022) .... But still lack of access to CI and services... WHY?

- Lack of awareness of CI ([www.ehima.com/surveys](http://www.ehima.com/surveys))
- Lack of referrals, audiologists and ENTs not aware of criteria
- Funding challenges particularly in low and middle income countries: (World Hearing Report, 2022, WHO)
- Problems with hearing screening programmes – for adults but even for children eg in the UK : [www.dailymail.co.uk/news/articles-121561115](http://www.dailymail.co.uk/news/articles-121561115)
- Problems with CI services eg S Australia where children not being well managed after CI (Messenger, A. 2023, November 8).
- Lack of follow up processes and traceability
- Education – parents' biggest problem
- So..

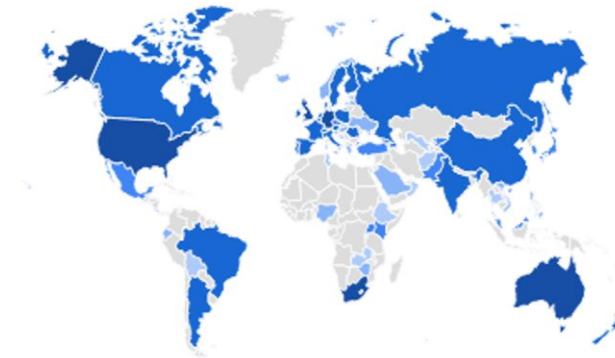
# MEET CIICA: CI INTERNATIONAL COMMUNITY OF ACTION

- A growing global network of CI Advocacy groups, CI users, families, professionals, industry, public health officials and other stakeholders
- Increasing access to the provision of CI and lifelong CI services globally.
- Providing CI advocates with resources they need: global online Conversations, sharing advocacy successes and challenges

630 individuals

112 organisations

72 countries.



Join us!

[www.ciicanet.org](http://www.ciicanet.org)

**Part of the World Hearing  
Forum, WHO  
Alliance, Advocacy, Action**



# Our online survey of adults with CI

- A global survey with both qualitative and quantitative questions
- The views of adults with CIs about their experiences of the services they receive
- Over 1,000 responses from 40 countries
  
- Results: high satisfaction rates even in the older patients... BUT ..**
  
- Little or no rehabilitation for adults**
- Challenges in managing the technology long term**
- Ongoing funding challenges which could lead to non-use**

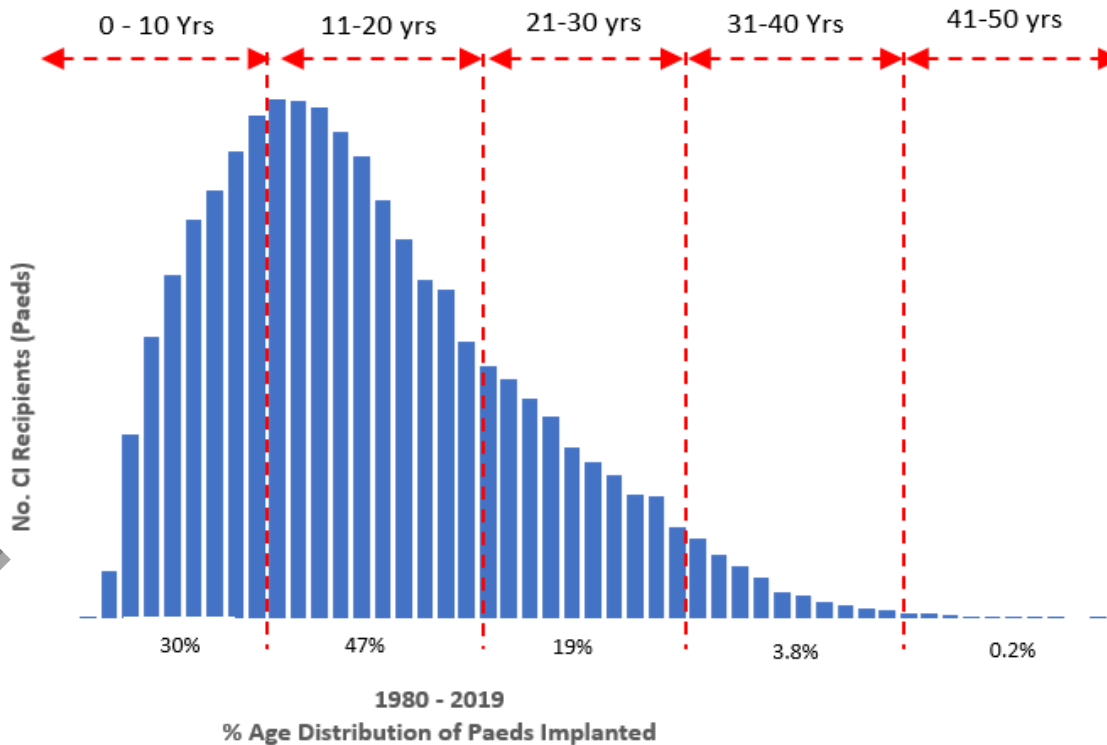
# Young adults with CI

- ❑ 105 respondents were implanted as children and are now adults
- ❑ The views of the first group of young adults who received CI as children
- ❑
- ❑ Growing up hearing with CI
- ❑ *“we are the new stakeholder group!”*



# Children with implants – grow up....!!

Europe CI Paediatric Recipients Implanted (Current Age Group)



**70%**  
estimated  
over 11  
and over  
20%  
estimated  
over 20

# What did this group of young adults tell us?

## High Satisfaction with CI:

**72%**

VERY  
SATISFIED

**24%**

SATISFIED

**4%**

NOT  
SATISFIED

## High Satisfaction with CI Services:

**56%**

VERY  
SATISFIED

**40%**

SATISFIED

**4%**

NOT  
SATISFIED

# Satisfaction is high with CI

- *My cochlears have given me a life I never would have had. I'm able to attend school and college, work and support myself, and enjoy laughing with friends and family as well as music and things other kids enjoy. I am forever grateful!*
- *Am so used to it **without my CI can't do anything.***
- *Super satisfied!*
- *I've always heard through a cochlear – so it's all I know.. Without my implant I can do nothing....*
- **This is a huge responsibility for us all working in CI services**



# What would they like?

- **More robust**, waterproof, staying on in sports
- **Regular maintenance** : *Its important for people to know who they can go to when their implants aren't working, if they need spare parts and so on.*
- **Accessible appointments**: *Communication for appointments is not accessible and creates problems*
- **Greater control**: *I want to manage my own settings*

# Specific challenges to these young adults:

- This group are the first to grow up being deaf but hearing with CI
- **Lack of understanding of needs (CI can work too well):** *we talk well, but we actually remain deaf and don't have perfect hearing in many situations*
- **Meeting others :** *It impacts our social, mental health, culture and knowledge. Its important that CI users should be connected to each other and be confident that they are not only ones with this experience*
- **Opportunities to advocate:** *It is hard to feel that you constantly have to fight for what you deserve even if is in the law.*
- **All the while, we could be deaf again in a snap.** *It's frightening and hard to think about.*

# Lifelong services : for 90 years and more...

- *Many people get their cochlears 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 issues the older generation knows nothing about***
- ***Plus all the lifetime issues** that we are going to face in an ever changing world of medical growth- the devices must be maintained, upgraded and repaired.*
- ***I will have my CI s all my life. I should have support for them all my life.***
- ***Ongoing costs; they are not financially secure:***
- *These costs are phenomenal and private insurance rarely covers.*
- *We wish the high prices for our CIs would come down, it is impossible to get the new accessories, new processors etc*

**High  
satisfaction  
with CI**

**Provision  
of lifelong  
CI services**

**Funding**

**Reliance on CI  
for communication  
in everyday life**

# Young Adults with CI Matter : new CIICA report

- Go to [www.ciicanet.org](http://www.ciicanet.org)
- *We are the first deaf group of young people with CI who are stepping into the hearing world..... Everyone here, united across the globe....*

## YOUNG ADULTS WITH COCHLEAR IMPLANTS MATTER

A global consultation: the experiences of young adults who received cochlear implants as children

Authors: Sue Archibolt, Corrie Mayer, Brian Lamb and Qais Khan

## YOUNG ADULTS WITH COCHLEAR IMPLANTS MATTER

A global consultation: the experiences of young adults who received cochlear implants as children

### CONTEXT:

- 34 million children globally have hearing loss.
- Cochlear implants (CI) provide useful hearing for children whose level of hearing loss/deafness is too great to be helped by conventional hearing aids.
- There are now estimated to be over a million people with cochlear implants, including about 300,000 children (industry estimate).
- Cochlear implantation in children has been proved to be safe, effective and cost-effective.
- Cochlear implantation involves the process of assessment, surgery to implant the internal device, the fitting and maintenance of the external speech processor and rehabilitation.
- Those children who were among the first to receive cochlear implants are now young adults and there has been little research into their experiences as the first group to grow up with CI.

### A SURVEY AND CONVERSATIONS TO IDENTIFY THE KEY ISSUES FOR YOUNG ADULTS WITH CI:

- Using the subset of data for this group from the Global Adult Survey:
  - Survey developed with CI users, in six languages
  - 105 who were implanted below the age of 18 responded to the survey as adults
  - Respondents from 15 countries
  - 26% implanted at 2 years of age and under.
- Summaries of seven global CIICA Conversations on the issues raised with Young Adults with CI.
- Survey of the Advisory Group of Young Adults with CI.

### WHAT DO THEY TELL US?



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**Global Conversations  
Young Adults with CI  
about the issues they  
face going into  
adulthood: university,  
social life, travels,  
workplace, managing  
the technology**

**Led by Qais Khan**





**Launch of Young  
Adults  
Agenda for Change  
International CI Day  
25 February 2025**



**CI have given these young people a voice!  
They want to use this voice to ensure that CI services  
are sustainable  
What is our responsibility to them?  
To learn from each other and listen to them**

