

INTRODUCTION

CIICA was established on International CI Day, 25 February 2021, following a global consultation about the possible development of an organisation focussed on CI advocacy. The respondents wished to work together in a global network, to increase access to CI and the lifelong services necessary. The report of the consultation formed the basis of the Foundation Report of CIICA, available from www.ciicanet.org. Volunteers from the consultation formed the Steering Group of CIICA, the majority of whom are CI users or family members, with committed Founding Members, including leading global organisations and individuals, with the clear goal of giving users and families a voice in increasing access to CI provision and services.

United by a common mission to increase access to, and support for, cochlear implantation.

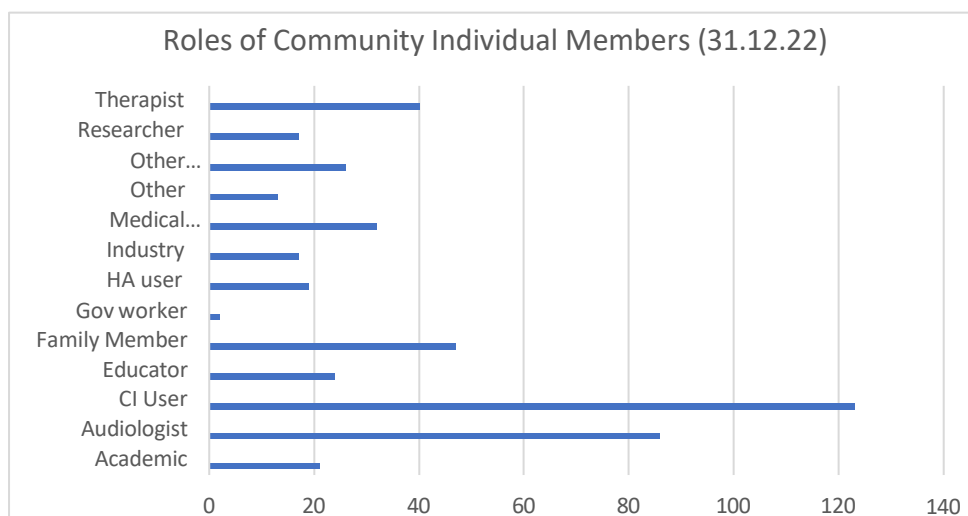
In its first year, the CIICA network grew across the globe, in membership, activity, reach and impact. This report of the first full year, 2022, summarises that activity and the governance review which has led to a change in status to an international NGO, based in Brussels.

MEMBERSHIP OF CIICA

As at end of December 2023 we have 463 individuals and 94 organisations in our community representing activity in 59 countries across the globe. See list of countries in the Appendix and member organisations at [Community Members – CIICA \(ciicanet.org\)](http://Community Members – CIICA (ciicanet.org))

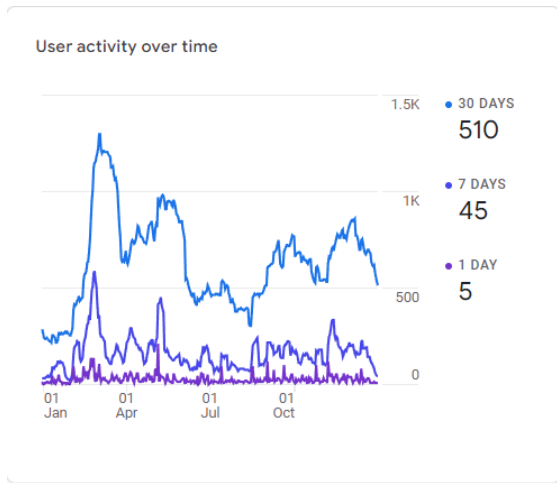
Top countries: UK, USA, Australia, Belgium, Germany, Canada, South Africa.

The reported major roles of individuals are shown here (although some have more than one): and CI users are the most common group. It should also be noted that many of the organisational members are organisations of CI users and therefore the reach into the CI community is much wider and deeper than the headline numbers would suggest.



WEBSITE ACTIVITY

A major recommendation of the consultation was for an active website to act as the community sharing resources, research and activity: the CIICA website is primarily for the network, not an outward-facing website. Therefore, we do not anticipate huge numbers, but rather that network members share the information themselves with colleagues and families.



However, activity has continued to grow: the following figure shows measures of activity over the year; the average number of users over a 30-day period has increased by 64% during 2022. Peaks can be seen on our birthday (Feb) and in May when people were responding to our membership survey. Peaks appear after each issue of our CIICA UPDATES.



Activity also increased when we our website was provided in other languages; by end of the year we provide information in over 40 languages. Top 10 languages used: English, Dutch, Spanish, German, French, Danish, Portuguese, Chinese, Finnish, Italian. The top countries accessing the website: UK, USA, Australia, Netherlands, Finland, Canada, Germany, France, India, Belgium, Austria, Brazil.

Activity Summary: for the year 2022

Looking at the users and activity over the year:

| Activity | Quarter 1 | Quarter 2 | Quarter 3 | Quarter 4 | To date 2022 |
|-----------------|-----------|-----------|-----------|-----------|--------------|
| User engagement | 6K | 5K | 4.5K | 4.4 | 19.9K |
| Users | 1.8K | 2K | 1.6K | 1.8K | 7.2K |
| Events | 22.5K | 21K | 19K | 21.2K | 83.7K |
| First visit | 1.8K | 2K | 1.6K | 1.7 | 7.1K |
| File downloads | 510 | 490 | 532 | 668 | 2.2K |
| Page views | 7.9K | 7.1K | 6.2K | 6.8K | 28K |

Pages in order of visits:

Home page, Events, News, Resources, Community Members area. The Living Guidelines with the linked Conversation summaries and the information on the Survey are popular.

It was encouraging to see the Community Members area of the website increasingly used to share news, events, resources, and stories. Resources from CIICA and members are increasingly downloaded. We are also aware that many national and local networks then share the resources they have download onwards within their own networks. We have no direct way of measuring this but informal feedback suggests this leverages the impact of the resources many times over as many of the networks have hundreds of individual members who then receive the CIICA resources.

COMMUNICATION AND ONLINE ACTIVITIES

CIICA now has two main online events which are now well established, and provided with live captioning in English as well as in other languages by request:

CIICA LIVE Events have presentations on specific requested topics important to users and families every 2 months; these promote discussion through the chat room. The majority of presentations are delivered by CI users and families and the captioned presentations are available afterwards at [Events – CIICA \(ciicanet.org\)](#). These events typically attract about 100 registrations from about 30 countries. Topics in 2022:

- The Impact of the Pandemic on CI users, families and services
- The Global Barriers to CI for Children
- Young People with CI, our challenges and opportunities
- Our Adult Survey, Exploring the Issues

CIICA CONVERSATIONS: small groups (max 20) having a facilitated discussion on a specific suggested topic for one hour. There are no presentations, but a summary of key issues which emerge during the conversation is shared on the website and in members' social media and own sites. Summaries of the Conversations available at: [Events – CIICA \(ciicanet.org\)](#). Topics in 2022:

- Life with CI: 18-30's Together we can shape our future
- Adult Services after CI: Reimagining Rehabilitation
- 18-30's: How does CI influence our Human Connections?
- Adults with CI: managing Listening and Cognitive Effort
- Experiences of Tinnitus and CI
- Four Conversations on the Living Guidelines Project.

The CIICA conversations have become an important resource for developing and refining policy positions of participant organisations and establishing what issues are most important to the network. The summaries of these sessions are also highly valued as tools for developing further thinking and recording the views of the sector.

CIICA UPDATES

CIICA updates are sent to members every two weeks: information about online events, resources, members' news and activities, research news. These are shared through the network, and result in increase in website activity. Over 50% opened within three days.

RESOURCES:

In addition to sharing the resources of members, CIICA has produced useful resources available from www.ciicanet.org/resources:

- For our First Anniversary our members provided videos about the impact of the pandemic in their region – and these were collated in collaboration with one of our members, PINDROP, New Zealand. Go to www.ciicanet.org/resources to view these inspiring captioned videos and stories.
- Why Hearing Well Matters for Healthy Ageing, with EURO-CIU
- Cochlear Implants for Deaf Children, with EURO-CIU
- Living Guidelines Project Conversation Summaries
- CIICA guides to the World Report on Hearing for Adults and a separate one for Children.

Translations for these resources are done by volunteers from the network and have proved to be very popular with members.

RESEARCH:

Cochlear Implants in Deaf and Deafened adults: a global consultation on lifelong aftercare

We are delighted to have received a small research grant from Social Sciences and Humanities Research Council, Canada, via York University, Toronto, with the Principal Investigator, Professor Connie Mayer.

Specific objectives are:

1. To gather global information on the rehabilitation provision and needs of deaf and deafened adults after cochlear implantation.
2. To identify the long-term technical support provided and required after implantation in the views of adult CI users.
3. To analyze the information by country, age at implantation, and length of time implanted to ensure that support is responsive and sensitive to contextual and cultural differences.
4. To develop a report on the range of services and supports currently provided, and those that adults users identify as areas of need, with recommendations.
5. To channel knowledge and insights gained from the proposed research directly into the work of CIICA and to the existing academic research on cochlear implantation in adults.
6. To work collaboratively with the global community of adult CI users to empower user led advocacy to influence governments and health funders in addressing CI provision.

The survey was translated into six languages, checked by our user members and disseminated widely. We had over 1000 responses from 30 countries, with many rich thoughtful responses. The summary of the first high level analysis is on our website, and been well visited. The 3,500 qualitative responses have been translated and are now being analysed. The research has been presented at will result in more presentations, peer-reviewed papers, and a summary report to be used for advocacy work.

COMMUNICATIONS AND ACTIVITIES WITH OTHERS

Living Guidelines Project

The goal of the Living Guidelines Project is to increase access to CI and to provide recommendations for evidence based practice for adult CI services. CIICA's Chair, Leo De Raeve, is one of the key leads for this project and CIICA is pleased to contribute the users' perspective into the process. The project

is shared on our website and is popular, with the resources available there. The involvement of CI users and families will be important in its dissemination. The Living Guidelines is prominent in our CIICA UPDATES, and Leo De Raeve has presented on the project at several conferences, including IFHOH World Congress in Budapest and IFOS in Dubai.

Four CIICA CONVERSATIONS were held to produce summaries of user and family comments on the guidelines and on the issues which should be included. Attendees were keen to use the opportunity to influence the report and its recommendations and keen to be part of **“this marvellous opportunity.”** Summaries of the issues on what should be included, and how the Guidelines could be used for advocacy work are on our website, and a final summary will be produced for advocacy resource. CIICA’s input has already had an impact on the report and its forthcoming recommendations.

Communications with others:

- Social media increasingly used: Twitter feed.
- Items in members’ newsletters, blogs, ENT News
- Part of the MakeListeningSafe Campaign, with WHO
- CIICA has presented papers at the IFHOH World Congress; HEAL, Como; EURO-CIU/ONICI/OPCI conference, Rotterdam; British Cochlear Implant Group Conference
- Applied for membership of the World Hearing Forum.
- Paper for publication about the development of CIICA as an example of a Global Health Network submitted for peer review.
- Regular participation in Lehnhardt Foundation parent webinars for Russian Federation
- Facilitating adult work across the Nordic countries including producing a declaration which although separate from CIICA funded activity has fed into the network, and beginning to do similar work with Canadian CI users and hearing loss organisations which will also feed into CIICA resources and links.

FINANCE

Financially, CIICA performed as per our budget for 2022; the exception being the costs of becoming a legal entity proving more than forecast.

Income was 104,954 Euros and Expenditure 85,915 Euros. Income does not include 6,000 Euros from research grant to come. Sources of income: Advanced Bionics, Cochlear, Private donations, a research grant from Social Sciences and Humanities Research Council, Canada.

The International Federation of Hard of Hearing (IFHOH) continued to act as our bankers for CIICA for 2022 and we are very grateful for this. In the next section we describe our Governance Review and the decisions made and the changes to our banking arrangements. When the final process of becoming CIICA.AISBL is complete, we will have our own bank account with KBC International in Belgium.

We are grateful for the support of our funders in helping establish CIICA and in providing the basis for establishing us as an organisation. CIICA will be focusing on developing our relationship with existing and new funders as we seek to put the organisation on a long-term sustainable basis and to be able to increase the support we give to the network.

GOVERNANCE REVIEW

As planned, a Governance Review of CIICA began in April 2022 by the Steering Group and its consultants. The Steering Group was clear that CIICA should continue to function in the flexible and inclusive way it had done during its first year, and build on this, while recognising that CIICA needed to become a legal entity and have its own banking facilities. This follows an assessment that the need for the network had been more than demonstrated and followed the very positive feedback from the CI sector globally. We have been very grateful for IFHOH for enabling us to come this far, and manage our banking, but there were challenges in obtaining and managing grants, for example, without a legal entity and CIICA’s own bank account.

This led to the decision for CIICA to become an AISBL (Association International Sans But Lucratif) based in Brussels, Belgium. This has involved a period of complex and intense work to establish the best legal form and then establish the organisation. The Statutes were drawn up with a lawyer and a notary appointed to take the Statutes to the Ministry of Justice. They were signed 6 December 2022, and in January we hope to have them confirmed, and then to establish our own account.

Leo De Raeve confirmed as Chair, Harald Seidler as Vice Chair. Ruth Warick as Treasurer and Sue Archbold as Co-ordinator. Our Steering Group has a majority of CI users and families. Our Communication Group, all CI users, are Full Members, according to Belgian law.

SUMMARY

In its first full year CIICA has:

- Established a growing global CI network, with greatest group being CI Users, and family members with a membership from 59 countries
- Established the CIICA Steering Group, with majority membership of users and family members and global representation
- Established a Communications Group which is entirely of adult CI users
- Established an active website, with shared resources, topics, discussions, research
- Interactive online monthly events, on topics defined by users and families and showcasing user advocacy activities and issues globally to inspire each other
- Increased accessibility with 40 languages available to users, and providing captioning in language of choice for on line events
- Produced online resources on Summaries of the World Hearing Report on CI evidence, and on Why Hearing Well Matters for Healthy Ageing, Cochlear Implants for Deaf Children. Translations carried out by user groups
- Provided a number of groups with the tools they needed to advocate for CI
- Participated in World Hearing Day and in WHO activities
- Delivered a number of papers advancing our case which have been very well received at International conferences.
- Obtained a grant from leading Canadian funder to explore the topic most raised as an issue by adult CI users
- Delivered on budget and time.
- Completed the process to become an AISBL, based in Brussels.

This development has only been possible with the support and commitment of the Steering Group and working groups as well as a number of committed individuals which has enabled us to achieve these objectives and established CIICA as a vibrant and engaging network enabling CI users, families, and young people to have their voice heard. The budget and business plan for 2023 for CIICA as an AISBL has now been agreed and we look forward with the new structure to further global development, led by CI users and prospective users, and their families.

Brian Lamb and Sue Archbold, on behalf of the CIICA team, 3 January 2023

With thanks to support from: Advanced Bionics, Cochlear, Private donations, and a research grant from Social Sciences and Humanities Research Council, Canada.

OUR INTERNATIONAL STEERING GROUP:

Teresa Amat, Parent, Speech Therapist, President European Association of CI Users (EURO-CIU)

Leo De Raeve, PhD, (Chair) , Director, ONICI, Scientific Advisor to EURO-CIU, Belgium

Qais Khan, CI user and advocate, UK

Eddie Mukaaya, Parent, Founder and Executive Director Hear His Voice, Uganda

Barbara Kelley, Executive Director of the Hearing Loss Association of America (HLAA), USA

Darja Pajk, CI User, Occupational Therapist, Board Member of European Federation of Hard of Hearing

Lee Schoushkoﬀ, Chief Executive NCIT, PINDROP Foundation, New Zealand

Harald Seidler, MD, (Vice Chair), CI User and ENT specialist, DSB, Germany

Ruth Warick, HA user, Past President, International Federation of Hard of Hearing (IFHOH)

OUR COMMUNICATION GROUP:

Anita Grover, CI user, Chief Executive AVUK

Lise Hamlin, CI user, Director of Public Policy, HLAA, USA

Qais Khan, CI user and advocate, UK

Robert Mandara, CI user, Vice President EURO-CIU, Finland

Our Co-ordinator: Sue Archbold, PhD

Our Public Policy Advisor: Brian Lamb, OBE

Appendix:

List of countries of members:

Afghanistan, Argentina, Australia, Austria, Belgium, Bolivia, Brazil, Canada, Chile, Cyprus, Czech Republic, Denmark, Ecuador, Egypt, Estonia, Finland, France, Georgia, Germany, Guatemala, Iceland, India, Iran, Ireland, Israel, Italy, Japan, Kenya, Libya, Luxembourg, Malaysia, Mexico, Mozambique, Nepal, Netherlands, New Zealand, Nigeria, Pakistan, Panama, Poland, Portugal, Romania, Russia, Saudi Arabia, Singapore, Slovenia, South Africa, Spain, Sweden, Switzerland, Thailand, Tonga, Turkey, Uganda, UK, USA, Uruguay, Vietnam, Zimbabwe.