# THE FOUNDATION DOCUMENT

## Based on a global consultation

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**CIICA**
COCHLEAR IMPLANT INTERNATIONAL
COMMUNITY OF ACTION

# THE FOUNDATION FOR CIICA: WHO ARE WE?

The issue addressed by CIICA is the massive gap between those who could potentially benefit from CIs and those who have them: only 5-10% of those in developed nations with severe to profound deafness and hearing loss have a CI, in spite of the benefits to individual and society being well proven, including the cost effectiveness.

The proposal for CIICA to address this issue globally followed an international consultation with key stakeholders about the role of CI advocacy work and its strengths and challenges. This consultation arose from the agreements and interest expressed at a meeting of the Consumer and Professional Advisory Committee (CAPAC) including all industry stakeholders in Geneva in December 2019, where the International Consensus Statements on adult cochlear implantation (CI) were presented. COVID 19 has clearly impacted on funding and practices for CI services worldwide and the potential for CIICA has become even more important and timely.

We describe CIICA, its goals and plans and provide the responses of the consultees which drive this initiative.

**CIICA provides an opportunity for a new way of working for CI advocacy groups, bringing them together with opportunities for sharing and collaboration to strengthen the user and family voice.**

## OUR VISION FOR CIICA

The vision of CIICA is a world in which awareness of the benefits of CI are well known to those with deafness and hearing loss, their families, professionals in the field of hearing care, the general public and public health decision makers. A world where access to CI and lifelong support is available to all appropriate.

## OUR GOALS FOR CIICA

To increase the number of children and adults globally who have access to cochlear implants and lifelong aftercare by:

- Raising the international global awareness of the health, social and economic benefits of cochlear implants for those who could benefit from implantation, health care practitioners and wider society.

- Empowering user led advocacy and awareness raising activity to influence governments and health funders to invest in addressing the under provision of CIs and other implantable technologies, related habilitation, after care and up-grades.

- Supporting CI advocates with the tools they need to achieve change.

## OUR IMPACT

The impact will be improved access globally to cochlear implantation, rehabilitation, life-long technical support including processor upgrades and aftercare driven by CI user advocacy initiatives.

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## HOW WILL WE ACHIEVE THIS: OUR AGREED OBJECTIVES

- To share user driven advocacy activity via a shared digital platform becoming the Community of Action:
- To empower CI user/family groups globally
- To increase awareness of the benefits of CI
- To increase referrals for CI and access
- To foster collaboration across the CI sector
- To enhance the global impact of user advocacy on CIs
- To influence public policy decisions on hearing health and CI
- To improve lifelong care for those with CI
- To provide an opportunity for data collection, and user driven research on CIs
- Develop and support advocates to become regional and global leaders in their community and have greater impact internationally.
- To exchange resources

## HOW WE WILL WORK TOGETHER: OUR VALUES

The community of action will share the following values: it will be:

- Independent
- Collaborative
- Sharing
- Inclusive
- Empowering
- Promoting Trust
- Diverse
- Accessible
- Transparent

**"**

**Only chance of success is the advocacy voice – use the advocacy voice with the policy makers/influence decision makers/voice of the end user … give the megaphone to a group of individuals to enact change: it's too professionally based – they forget the user end of things.**

## TO ENSURE THESE VALUES WE WILL:

- Agree our vision, goals, objectives and values
- Maintain a professional and a respectful relationship with all community members
- Value the activities of other affiliates
- Give advice and support to the Chair and Co-ordinator and Steering Group in achieving the aims of CIICA
- Work with honesty, transparency and integrity at all times, ensuring that a consensus approach is maintained to achieve the aims of CIICA
- Try to achieve consensus where possible and respect people's and organisations' views where this is not possible
- Keep the overarching goals in mind, while recognising different priorities in different places and systems and valuing diversity
- Be willing to share resources and collaborate to achieve the aims of CIICA: to obtain permission before using another's work and always to acknowledge others' work.

## WE WILL INCLUDE:

- Voluntary organisations and groups and individuals involved in advocacy work
- Patient and Industry Advocacy Groups and individuals
- Professional organisations involved in CI and hearing loss
- Policy groups and institutions related to hearing loss
- Academic institutions with links to policy work
- International agencies with an interest in hearing loss
- Governments and funding decision makers

# THE CONSULTATION: PROCESS UNDERTAKEN

A worldwide consultation took place, using qualitative research techniques, to identify issues about CI advocacy important to respondents.

The consultation began with the CAPAC group, then was expanded to other global key stakeholders, including user/family groups, NGOs, health care professionals and industry. Open interviews were undertaken with 32 individuals from 22 countries, followed by a wider survey of 63 individuals from 28 countries. The results were analysed by the consultants and an independent researcher. Further consultations took place with members of the CAPAC group as the themes and recommendations emerged to ensure that our interpretation was appropriate.

### THE ISSUE ADDRESSED

There is a massive gap between those who could potentially benefit from CIs and those who have them. Just 5-10% of people in developed nations with severe to profound bilateral hearing loss obtain a CI (De Raeve et al 2016; Sorkin & Buchman 2016; Raine et al 2016; Vickers et al 2016). In part this is caused by a lack of awareness of the impact of hearing loss and deafness in childhood or adulthood and also the lack of awareness of the benefits of implantation by potential users, healthcare professionals, policy makers, and funders of health care. This leads to the lack of appropriate and timely referrals, with restrictive access criteria, a lack of funding, and often poor or inconsistent aftercare (D'Haese et al 2018; De Raeve et al 2020). Additional challenges exist in low and middle income countries. Advocacy groups, including user and family groups, have increasingly contributed to the planning of public health initiatives globally in recent years, and those involved in hearing care and CI provision have also been increasingly active. However, these hearing care and CI initiatives are often fragmented and there is a need for a unifying voice for users of CI and their families in promoting access to CI, and the required long-term management.

**Advocacy groups, including user and family groups, have increasingly contributed to the planning of public health initiatives globally in recent years, and those involved in hearing care and CI provision have also been increasingly active.**

## SUMMARY OF THEMES FROM THE CONSULTATION

- *The barriers to access to CI were agreed:* lack of awareness leading to lack of referrals and insufficient funding (not perceived by decision makers as important). The barriers appear to be much greater for adults than for children and because these barriers appear likely to increase as a result of COVID-19, there is an urgent need for CI advocacy work.

- *A strong belief in the value of advocacy work* and the role of the user/family groups

- *Agreement re the key strengths of advocacy work:* prioritised diversity, increased grass roots action in time of societal change, powerful messages, decision makers listen to user groups, and 52 examples of effective global advocacy were given

- *Agreement about the challenges for advocacy work:* managing diversity, shortage of time, resources, mixed messages, too many organisations and bureaucracy, need for advocacy training.

- *Strong enthusiasm for and desire for advocacy action:* advocacy/user/family groups working together and sharing, leveraging the user voice globally for increased CI access and long-term management.

- *Suggestions for new ways of working:* a network, platform, coordination, a loose structure to facilitate joined up activity with the activity and organisation evolving over time.

- *Consensus on key goals and objectives of a global advocacy initiative,* and suggestions re possible structure, affiliations including global representation, its development, and a range of funding streams.

- *An interactive digital platform to be the hub of activity;* consensus about what should do: share resources, activities, inspire action, research and evidence …..and what not to do: "reinvent the wheel".

## RESULTING RECOMMENDATIONS

Our plans for CIICA reflect stakeholder views and our review of the current context and current models of working. The increasingly uncertain times due to COVID-19 make flexibility of approach, and minimising risk, while taking action stakeholders, increasingly important.
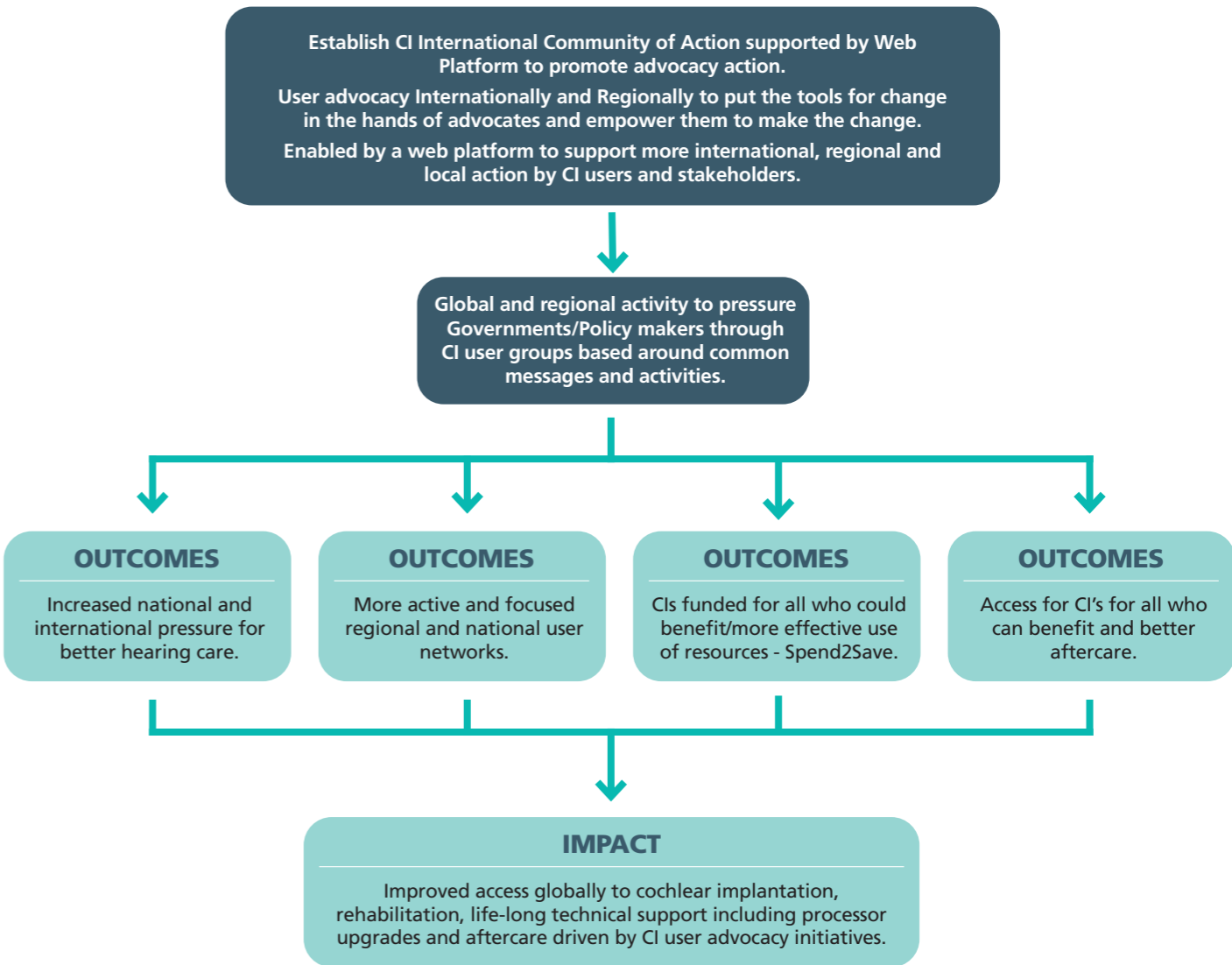
*We plan:*

- A CI International Community of Action (CIICA) to support activity at global, regional and national levels on greater funding, access and awareness of cochlear implants by politicians, health funders, policy makers and other key stakeholders.

- Fundamental is a digital platform to act as the fulcrum and base for this CI International Community of Action bringing together diverse advocacy organisations drawn from different regions of the world.

- That this is a supported global initiative not an organisation per se and is not a legal entity. It is a way of working together and agreeing joint initiatives and leveraging local activity.

- That this initiative is led by CI patient and family advocate groups but works closely with professional organisations, experts in the CI field, manufacturers and other stakeholders.

- That support and governance is through an Advocacy Steering Group with a Chair and Coordinator, with access to public policy and digital expertise, and regional representation.

- That one of the supporting organisations has a banker function of financial processing and legal grounding for funding bids etc. This is not a governance role.

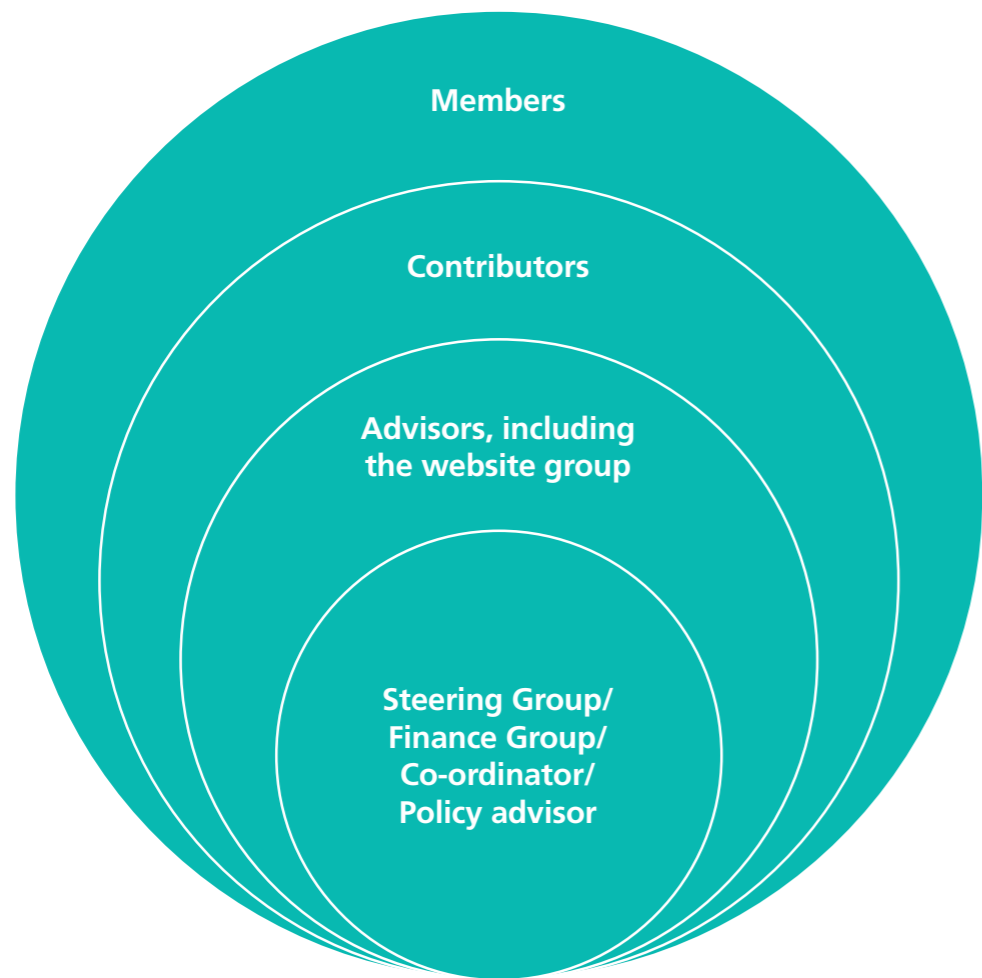- That mixed funding is sought.

# THE DEVELOPMENT OF CIICA

## CURRENT STRUCTURE

The following diagram illustrates the development of CIICA:



Establish CI International Community of Action supported by Web Platform to promote advocacy action.

User advocacy Internationally and Regionally to put the tools for change in the hands of advocates and empower them to make the change.

Enabled by a web platform to support more international, regional and local action by CI users and stakeholders.

Global and regional activity to pressure Governments/Policy makers through CI user groups based around common messages and activities.

**OUTCOMES**
Increased national and international pressure for better hearing care.

**OUTCOMES**
More active and focused regional and national user networks.

**OUTCOMES**
CIs funded for all who could benefit/more effective use of resources - Spend2Save.

**OUTCOMES**
Access for CI's for all who can benefit and better aftercare.

**IMPACT**
Improved access globally to cochlear implantation, rehabilitation, life-long technical support including processor upgrades and aftercare driven by CI user advocacy initiatives.

## SUGGESTED STRUCTURE

The following diagram illustrates a suggested engagement structure for a networked approach.



Members

Contributors

Advisors, including the website group

Steering Group/
Finance Group/
Co-ordinator/
Policy advisor

CI International Community of Action

Web based platform underpins and supports the Community of Action

Regional Groupings to be developed over time
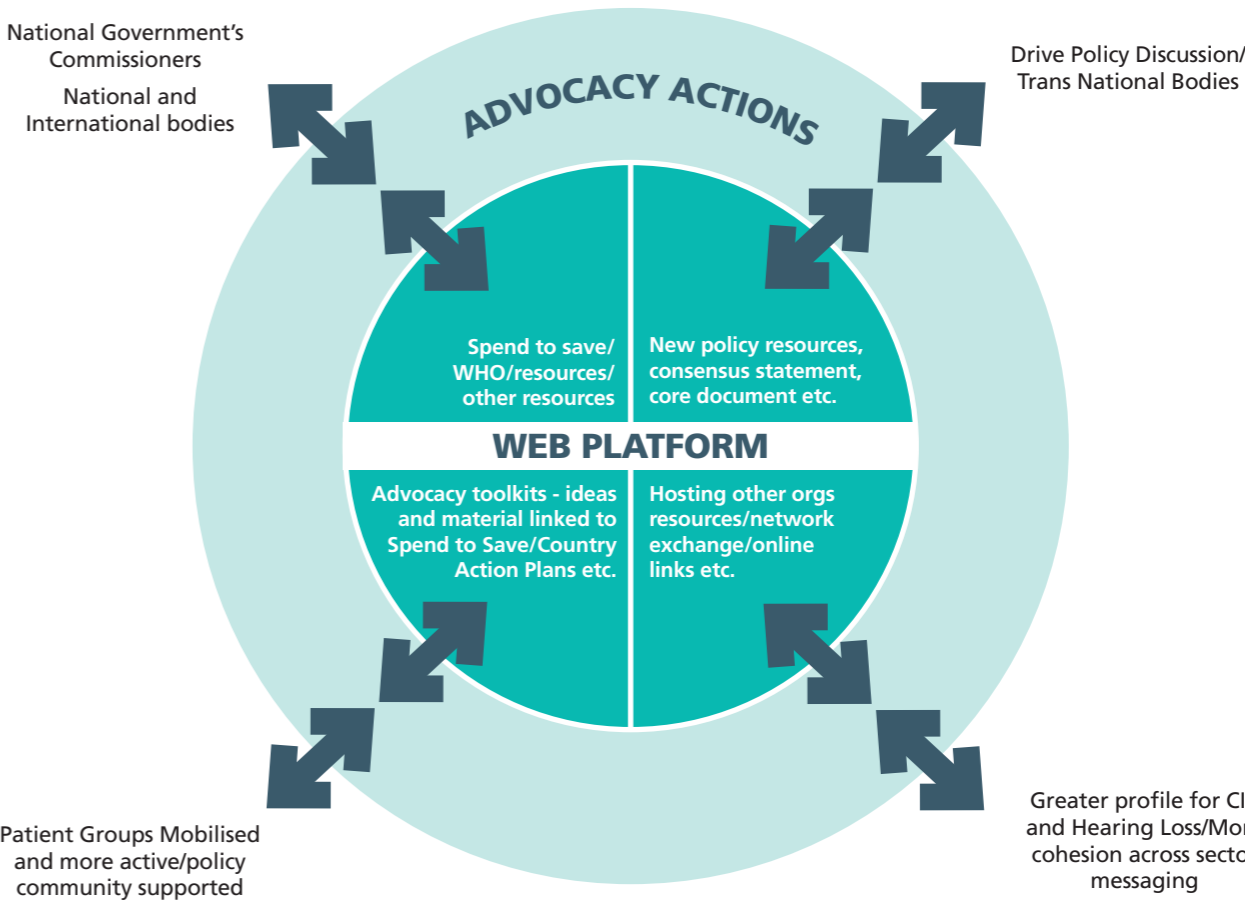
# DIGITAL PLATFORM FOR CIICA

The digital platform will be the key to the CI International Community of Action. In both the interviews and the survey, the need to create a 'platform' or website for a new advocacy initiative was central.

The following diagram illustrates how this platform will be the gateway to advocacy resources and a means to co-operate digitally, host meetings, working groups and redirect people to country campaigns and resources.

## THE FUNCTION OF THE CI ADVOCACY PLATFORM

- To be the home for organising and promoting the goals of greater access and funding for CI internationally, increasing the user advocacy voice

- To build capacity of national and international advocacy organisations and individual advocates by providing access to research, policy, national standards, information training and support

- To provide an online meeting space and support network

- To be a gateway linking back to partners which increases their profile and reach.

**CIICA provides an opportunity for a new way of working for CI advocacy groups, bringing them together with opportunities for sharing and collaboration to strengthen the user and family voice.**



National Government's Commissioners

National and International bodies

Drive Policy Discussion/
Trans National Bodies

ADVOCACY ACTIONS

Spend to save/
WHO/resources/
other resources

New policy resources, consensus statement, core document etc.

WEB PLATFORM

Advocacy toolkits - ideas and material linked to Spend to Save/Country Action Plans etc.

Hosting other orgs resources/network exchange/online links etc.

Patient Groups Mobilised and more active/policy community supported

Greater profile for CI's and Hearing Loss/More cohesion across sector messaging

# CONTEXT FOR THE DEVELOPMENT OF CIICA

## IMPACT OF DEAFNESS AND HEARING LOSS ON THE INDIVIDUAL, FAMILY AND SOCIETY

Deafness and Hearing Loss in childhood and adulthood are growing major health challenges globally. The most recent WHO estimate suggests that approximately 466 million people (or 6.1% of the world's population) were living with disabling hearing loss in 2018. This estimate is projected to rise to 630 million by 2030 and to over 900 million by 2050. The Global Burden of Disease study, which incorporated mild and unilateral hearing loss, estimated that the population with hearing loss rose from 1.2 billion (17.2%) in 2008 to 1.4 billion (18.7%) in 2017. For adults, hearing loss is now the highest cause of Years lived with Disability over the age of 70 *(Davis, 2016)*.

In adults, hearing loss impairs communication, has been linked to reduced social support from others and loneliness which, in turn, could increase health risks. More specifically, communication and social connectedness are critical to brain health, addressing dementia and maintaining cognition *(see Lamb and Archbold, 2019)*. Good hearing provided by today's technologies can help ameliorate the impact of hearing loss and cognitive decline and hence reduce the financial burden on health systems and impact on individuals and their families *(Livingston et al 2017, see Lamb and Archbold, 2019)*.

In childhood, deafness is associated with delayed language, educational achievements and social and emotional development. For children, new-born hearing screening followed by timely fitting of hearing aids and implantation supports the development of early communication skills and language, with known positive impacts on educational attainments and social and emotional development *(Ching et al 2018;Dettman et al 2016;Mayer et al, 2016)*.

Hearing well matters across the entire life span and hearing loss has become a serious public health issue that deserves appropriate and well-coordinated global action *(Davis, 2019)*.

## ECONOMIC IMPACT OF HEARING LOSS FOR SOCIETY

In a recent study the cost to the European Union (EU) of reduced quality of life due to unaided hearing loss of 25 dB and above was estimated to be 224 billion euros, and the cost to the EU of reduced quality of life due to treated hearing loss (hearing aid use) of 25dB and above, was estimated at 168 billion euros *(Shield, 2019)*.

Unaddressed hearing loss poses a huge global financial burden of over 750 billion US dollars *(WHO, 2017)*. Not addressing hearing loss has very significant costs to society associated with additional health and social care *(Shield, 2019; Huddle et al 2017; O'Neil et al 2016; Lamb et al., 2015; Archbold et al, 2015)*.

Investing in prevention, providing early support for individuals, increasing hearing accessibility in the community, and changing social attitudes towards hearing loss is a much more cost-effective solution than dealing with the consequences of unaddressed hearing loss *(see Archbold et al., 2015)*.

Investing early in hearing care results in increased independence, better health and cognition while reducing the costs of public services provided by hospital, doctors, and social care *(Mahmoudi et al., 2018; Simpson et al., 2016; O'Neil et al 2016; Xiao & O'Neill 2018; Crealey & O'Neill 2018)*.

Money invested in hearing care gives a Return on Investment of 10:1 in savings on health, social care and other costs *(Decall/AoHL 2013; Archbold et al., 2015; Kervasdoue & Hartmann 2016)*.

With regard to cochlear implantation specifically, it has also been found to be cost effective for both children and adults *(see Archbold et al, 2015)*. People fitted with cochlear implants highly value the associated reduced social isolation, greater employability and general wellbeing *(Ng et al., 2016)*.

## GLOBAL DEVELOPMENTS IN HEARING AND COMMUNICATION TECHNOLOGIES

In the past thirty years there have been huge technological developments in hearing technologies: new-born hearing screening, digital aids, cochlear and other implantable devices providing useful hearing for both children and adults *(Lamb et al., 2015; Archbold et al., 2015)*. There is recognition of the life-changing impact of these technologies: improving the language and educational levels of children, improving confidence and communication for adults, along with reducing the impact of hearing loss on social isolation and mental health and co-morbidities, improving employment possibilities *(Archbold et al.,2015; Wilson et al., 2017)*. New ways of delivering these services have also been developed but global development is patchy *(Davis, 2016)* and there remains a massive gap between those who could potentially benefit and those who receive implants.

> **Increasing awareness and encouraging governments to adopt more of these technologies through this new advocacy effort will improve the lives of people with hearing loss and reduce the cost burden of unaddressed hearing loss on societies.**

In addition to the developments in hearing technologies, communication technologies have also developed dramatically over recent years, making captioning services more widely accessible and more effective, and services such as Skype, Facetime and Zoom now enable those with hearing loss to communicate face to face. The new communication technologies have an impact on how services can be accessed, and the impact of the COVID-19 pandemic has vastly increased people's use of the technology in accessing audiology and health services *(Swanepoel & Hall, 2020)*. These technological advances influenced the responses to this consultation and informed the vision of how this global initiative can move forward.

## CHANGING ROLE OF ADVOCACY IN CHANGING TIMES

One of the major themes to come out of the consultation was the changing role of advocacy and the changed context for advocacy. The development of social media, networked working and the rise of highly motivated individual patient and parent and family advocates who can increase impact via social media means that some of the older models of static and more formally representative organisations are being rethought. The speed of this change was enhanced by the impact of the pandemic with greater involvement by the public in health information and evidence. More flexible ways of working bring with them challenges around accountability but also allow much greater participation, flexibility and speed of response and fewer, lower costs. These societal changes have ensured that advocacy has become widespread in many countries as one of the prime ways in achieving change in health systems.

The challenge is that advocacy campaigns need access to support, materials and the ability to leverage local activity with international standards and examples of improved provision to act as reference points.

> **Advocacy work can sometimes be of limited quality and relevance and it was clear from our consultation that groups and individuals would welcome training and support to be more effective.**

This has to recognise the time pressures on many advocates who are volunteers for organisations or citizen advocates. Engagement therefore needs to build from what they find relevant, supportive and achievable within their context.

The advocacy survey illustrated that there is significant advocacy work going on across large areas of the globe at country level, with a number of regional coalitions or activities across countries; in particular the European CI Users Group, *(EURO-CIU)*.

These would provide the basis for a more bottom up approach to capture the vibrant activity of local advocacy campaigns and networks who are already challenging the gaps in provision that research and our survey have highlighted. Some of these more regional and global initiatives are already in progress and could be built upon. The research we have undertaken suggests that there is a gap in supporting information, training and resources for country and international advocacy work. User and family advocacy groups are well placed to advocate in the changing context of health-care provision and the challenge of the pandemic, but they need resources and tools.

CI User Advocacy groups have been key to the progress identified in our survey and have achieved much in their own countries and regions. There have also been moves to ensure country work is aligned with the advocacy work of the World Health Organisation on Ear and Hearing Care. These activities, however useful, have to compete against other better coordinated and better resourced advocacy movements, and also tend to be regional and disjointed. It is vital to ensure that messages about hearing care and CI are well communicated and understand modern communications and good advocacy practice. Good advocacy communication depends on appealing to people's values and emotions not simply the 'facts' *(Lamb 2011; 2018)*.

> **Clear and united messages must be framed well and move the debate away from medical, cost and technical issues around implants to focus on improved communication and capacity of people to live their lives and save health systems resources.**

## THE IMPACT OF THE PANDEMIC

In this rapidly changing context, the pandemic has had a huge impact on the provision of CI services and will continue to do so in the foreseeable future. During the pandemic the public have become used to medical and public health debate being shared on the media and are likely to expect this in future.

We expect an increase in the expectation for user/patient/family participation in their care and in the process of implantation which makes the establishment of CIICA even more timely. Several issues emerge:

- The Pandemic has impacted on cochlear implant services in many countries, delaying surgeries and services, increasing the need for support services and increasing the role of many user groups.

- The management of health care services in response to the pandemic have created challenges for health care budgets, impacting on financial support for CI and another challenge for access and long-term management. In this environment, hearing care may not be seen as a priority for funding.

- More adults may think about implantation as a result of changed practices in managing COVID-19 creating greater problems of communication.

- Increased confidence in use of online platforms has led to increased use of telehealth services, with implant services for both children and adults providing more on line telecare and remote services.

- Increased confidence with social media during the pandemic provides another avenue for increasingly effective advocacy work.

# THE EVIDENCE BASE FOR THE DEVELOPMENT OF CIICA:
## Views from the consultation

In this document quotes illustrate commonly made points in interviews and survey: S indicates the quote from the survey, U that it was from a User or family interview, P that it was from a professional interview and IN that it was from an industry interview.

### VIEWS ON ADVOCACY WORK FOR CI – WHAT IS NEEDED?

**There was a strong consensus about the value and importance of advocacy work for CI: a survey of members by the Hearing Loss Association of America (HLAA) revealed that advocacy and public policy work were the top reasons for people joining their association. One of our respondents commented that:**

*Advocacy work is so important that it's Advocacy work that makes the difference to different rates (of implantation) across countries. (U4)*

Respondents talked about the changing nature of society, where people expect to be involved in their own heath care and decision making with one CI user commenting:

*"They are the shop and I am the customer….." (U13)*

**Advocacy work needed to be fast, speedy, flexible and responsive and active (U6) to be successful. It is about:**

*Changing attitudes, policies, practices, coalescing together, networking for the greater good of individual and society. (U15)*

With the clear recognition of the value of advocacy work, several respondents mentioned that in the CI field, with services based in medical settings, the user voice often is omitted and that this needs addressing – hence CIICA.

*Only chance of success is the advocacy voice – use the advocacy voice with the policy makers/ influence decision makers/ voice of the end user but think holistically/ the patient the family their social fabric. Give a megaphone to a group of individuals to enact change it's too professionally based – they forget the user end of things. (IN3)*

*Consumers have strong role to play – and need to be willing to talk. (U15)*

**It is also crucial to understand and take account of local circumstances and a one size fits all approach will not work in international initiatives which have to give enough space and flexibility to local approaches and the specific barriers they face:**

*I think that the situation of CI is different from country to country so the ways of approaches of advocacy might be different depending of country's needs. (S10)*

When asked what was important for effective advocacy work, clear messaging and collaboration between professionals, users and industry were the most common responses.

*Important the general umbrella should be multi-disciplinary. Most important to is to have user groups, professional organisations and audiology and ENT should be represented. Also CI companies. Need some CI experts. These are in the network. (P3)*

**Where groups are working together, the message needed to be given with one voice – to bring together the separate groups:**

*Lot of work done by separate groups but it was the coming together in one voice (that made success). (P3)*

*Common messaging vital. (U7)*

**Another theme in the successful advocacy stories was the focus on clear goals and campaigns:**

*For successful advocacy work need to provide concrete examples of what advocating for -and be clear; focus on a few goals – small steps. (U15)*

**This requires planning and strategy:**

*Advocacy worked – when there was real partnership, leadership and a plan.*

When asked about examples of successful advocacy work in the survey, 52 very full open responses which were given; illustrating how effective advocacy work by user groups can be. Common themes which emerged were the lobbying of health ministers, politicians and decision makers, influencing changes in health policies in relation to ear and hearing care. Examples were given of the establishment of new-born hearing screening, of audiology services, of CI provision including funding, bilateral and upgrades. There were several mentions of familiarity with human rights, quoting them and the usefulness of WHO facts sheets and data. When asked about the most important activities, meeting government and decision makers and politicians were the most commonly mentioned, alongside working with allied professionals, trying to gain funding – not just for access but for long term management.

**It is important that you create activities for advocacy for CI on 3 different levels:**

*Focussing on decision makers, professionals and on possible CI-candidates and their environment (public). The most important activities can differ from country to country. They can even change over time, depending on the local situation. (S14)*

Finally, successful advocacy requires financial support, but the comment was frequently made that actually not a huge amount is needed to make a huge difference. The point was made that the use of today's technologies in an increasingly confident society can reduce costs considerably, particularly using virtual meetings and communication.

## VIEWS ON CHALLENGES FOR THE NEW ADVOCACY INITIATIVE

While there was a consensus on the key part played by users, there were several points about the challenges they face in this. User/family advocates are often volunteers: they have a day job or commitments too and there is often an expectation that they will work for advocacy for free in their spare time. This provides multiple challenges – managing a hearing loss with its extra demands, managing the technology (remote controls, phone links, captioning etc.) in differing environments, managing one's confidence, and one's family and job commitments and finances.

Several users made the point that when one has a hearing loss, to advocate is a real challenge: to follow fast moving conversations in often poor acoustic conditions, can make one lack confidence to take on this role.

**For example:**

*It is hard to advocate for oneself when you don't understand or mishear. Its invisible nature (hearing loss) – the mental adjustment needed. (U15)*

*You are terrified of saying things wrong, if suddenly deaf you don't have information on captioning, signed support – you need training in assertiveness – confidence gaining. (U2)*

When asked about the constraints and challenges of collaboration and sharing, the most common spontaneous response in the survey was time….

*Limited time of advocates. (S23)*

*The biggest enemy is time - Time constraints. (S10)*

*Lack of time (voluntary work of lots of us). (S11)*

*Time for meetings / creating plan of action/ […] ability of individual to follow through. (S20)*

*Time pressure on clinicians, disconnect between some types of research & practical clinical needs.(S15)*

**The challenges of bringing together different stakeholders and organisations was highlighted:**

*The collaboration should not slow things down (too many stakeholders, too many meetings) it must be efficient. (S47)*

The diversity across countries, regions, cultures and languages was mentioned frequently as a major challenge for global working, with the need to adapt messages and strategies to the local setting and stage of development.

*The different legislation in countries, the different mentality, the different level of CI availability, the difference in health systems. (S12)*

*Advocacy is different in different parts of the world and communication takes time and sometimes we suffer from 'old and outdated knowledge' - we should assure there is a place that is always updated - and we need it also in our native language. (S39)*

*Often have too many groups, associations which speak with different voices. So within country needs to be one voice. (P3)*

**In spite of these undoubted challenges, some strong statements were made about moving forward:**

*There should be none (challenges for advocacy initiatives). (S37)*

## VIEWS ON PURPOSE AND GOAL OF CIICA

There was considerable enthusiasm to develop advocacy work for CI and find new ways of cooperating at an international level, implementing at local and national levels.

*Hearing loss has real health consequences and has traction economically and therefore we need to take action – we have a story. Makes a huge impact on people's lives – but the user voice is missing – we need to galvanise multiple parties. (IN5)*

**It has already been clear that the support was for a user (consumer, recipient, client, and family) driven initiative reflecting societal changes. Some comments on this change:**

*Agreed that advocacy and lobbying work is sustained from the bottom up and not top down- needs to get away from old model of command and control where we issue documents and expect the world to follow what we say. (IN2)*

Establishing a platform, with consistent voice and messaging, and enabling users to have an equal seat at the table (or screen!) were the common demands for the goal of CIICA. This could become the "trusted place to go about CI"; a safe space for CI, with the main purpose sharing resources and activities: a common phrase used was "not to reinvent the wheel". Thus the "network" or platform could become the shared voice for CI becoming stronger, developing a community of CI advocacy action.

*United by a common mission and goals to maximise access to and support for implantation (adults is mainly what is being talked about). (P2)*

*Information sharing is by far the most important part of this development. If someone has started some good work – and has different strategies working – it's hard when we so far apart – everyone's stretched – there is lots of willingness to go forward. (U16)*

*To connect people and encourage them to be active themselves. (U8)*

*Of providing and sharing up to date information and resources (the huge benefit of Spend2Save work) volunteers don't have time or resources to do this – but to have the passion and the communication skills and access to decision makers. (U9)*

Opportunity for research leadership and consistent messaging across professional/consumer CI networks is key to global advocacy initiatives. (S44)

*It is really good idea to share resources and see what happens in other countries. This is crucial for advocacy work. (U17)*

*Facilitating countries – with core materials, resources which can be applied in our own countries (U6)*

*Consistency of messaging is most important, resourcing, public awareness. How do we get primary healthcare involved in public awareness. Needs a global initiative with bite size messaging that is consistent across the world. Modelling on areas that have worked to prove it's possible. Getting parents, and partners to work together and lead the advocacy at regional and local level. (U10)*

A common point made was that advocacy for CI needs to be included in the HL and Primary Care arena, if we are to increase referrals and awareness.

*CI advocacy needs to be included in the wider world of HL. (IN2)*

*Don't separate CI from HA – professionals dealing with HA need education in CI field – when it's the best solution for the patient. CI is a development of management of Hearing Loss (HL). (P6)*

*Raising Awareness – links with healthy ageing vital - and GPs and community care and hearing professionals. (IN3)*

Clarity of purpose and a clear message about what action was required in spite of the diversity noted.

**Moving this on requires advocacy training to ensure the human side and passion is balanced with the evidence and the message:**

*Training people on the waiting lists to become good advocates. Need the skills to be able to pitch the call for more funding. Important that advocates are trained and supported by people who are professionals in this area and can ensure impact. (U10)*

*Need to help people to find out themselves what is wrong -and how to identify marketing; a platform should help people to find the right info and to distinguish what is correct – give them the tools to do so. (U8)*

## DEVELOPING CIICA

The development of CIICA is based on the views of the respondents. The most common suggestions were for a "loose structure," a light touch, a network or platform, avoiding restricting structures.

*Loose network – which could evolve into something more – and share information and resources. (P7)*

*Structure – don't need a big structure – gets in the way. Lead/Chair – rotate. (IN3)*

*Makes a lot of sense to have a loose structure; could otherwise just get hung up on doing the structure.. Needn't be expensive to run, meeting virtually*

*Light touch, loose, coordination, not top down; networks need open minds. (U15)*

*NETWORKING – it's about relationships – and doesn't happen overnight. (U7)*

*A loose collaboration not an organisation. (U2)*

**A consistent theme of the comments was the need to start slowly and building up in collaborative ways:**

*Start low key – Network is non-threatening and then could move towards and evolve to consortium idea …….not set initial structure - a wider net- make it feel inclusive – set goals for first year and top line agenda and work up. (IN3)*

*Suggest forming working Groups and the body to come out of that……politics in this area kills efforts. This field not big enough to have divisions therefore joining up be helpful stop reinventing wheels: focus on 1 or 2 items to begin to transform. (IN1)*

There were many comments about the importance of bottom up models and the development of true collaboration. Terms such as non-threatening, evolving, loose at first, regional groups growing, building on current organisations and their work were used to describe the development of CIICA.

*Collaboration never works if you tell people what needs to be done. (U14)*

**There was a consensus about letting the organisation evolve:**

*Its effectiveness will be shown: – evolving over time. (U2)*

*New ways of working: we need to create the new landscape ourselves. (U16)*

The current changes in working practices with more on-line, more confidence and choice of technology seemed to lead people to suggest more flexible, organic, ways of working.

*For example: Modern concept needed – active. (U8)*

**It was also considered important that the "network" had real consumer/user involvement:**

*Consumer involvement in this- not just a seat at the table – want to be part of it and work together – drive it forward (see previous statements about being left out…). (U15)*

**A facilitator or coordinator role was suggested as vital within the structure, to facilitate sharing, collaboration, ensuring trust:**

*Ensuring talking to each other – like the idea of facilitator: Not helpful to go head to head but to work round things. (U2)*

*A facilitator is what we need – with common principles, others do job as best they can. (U6)*

*We need collaboration to make this work. Facilitator is really important – someone who has this on their minds and can put people in touch who don't know each other or what the other is doing. (U16)*

Although unnecessary bureaucracy was to be avoided, this initiative would not be without a structure to enable it to function and provide an element of governance.

*Needs governance not bureaucracy.*

**The strength of the initiative would be the collaboration of global groups, with shared goals:**

*Best by collaboration of different established groups throughout the world, affiliation rather than organisation. (P5)*

**Thinking about the issue of diversity and the challenge of managing this there were many suggestions that with a facilitator there could be regional advisors:**

*Regional leadership is crucial, and need to identify regional leaders that work more 'locally' to support local activities and leadership to make that happen. Modelling best practice locally. Need to find a central thread internationally and locally; organisations can then lead the local activity. Not a central organisation, but the ability to access support from the centre, but then support the regional areas to take action. (U10)*

## VIEWS ON A DIGITAL PLATFORM FOR THE CI ADVOCACY INITIATIVE

A digital presence to host advocacy activity and resources and become the community of action for CI advocacy was seen as essential.

*Website – vital – in some form – today if don't have a website presence you don't have a presence and validity is questioned ; needn't be expensive today. (U7)*

So what should it include?

*We don't want glossy brochures – you need to know the real things: simple webinars – videos – we just done webinars on telehealth and how to do. (U6)*

*Communication inclusivity , sharing activities, promote change, share resources - attracting people to join the movement - making resources accessible. (IN3)*

*A central repository or portal where issues are shared, resources can be shared and where learning from one country can be used and shared with others. If it provides links to documents, avoids IP stuff and gives a reason to belong. To share ideas, information and help problem solve: information as a Smorgasbord – take what you want from it and use it wherever you are. (P2)*

*There are many sources of good information; what's missing is an online channel of whatever type - website or other) to bring them all together and stimulate discussion that will support shared action across the UK. (S15)*

*Could also be used as a platform for online conferences and events which bring different networks together. (U5)*

*Within the resources part of the website-equipment to have webinars and other meetings and training.*

*Again could use company resources to do. Logistic support can come from the companies and content from the contributors. (P3)*

*A space for trusted information which could be translated into national languages – where info share – profs, parents, families and patients. (U14)*

Training in advocacy skills.

**The point was made that it needs to cover the lifespan. For example:**

*In Denmark we have access to CI but I think we still lack more knowledge in the follow up - both in clinics and via Telehealth. (S39)*

Any initiative needs to cover global diversity – languages and cultures. If this is done successfully, then action in one country can inspire action elsewhere.

*Website is crucial, needs loads of resources. Most important scientific papers, CI criteria, data. Using NICE criteria in UK helped in Belgium, needs more international comparisons to help systems level up. (P3)*

*Advocacy websites need to be different to reflect different cultures – and give different examples.*

Accessibility was seen as key for a platform driven by users; in addition, in some countries, electricity and access to computers could be challenging. Managing both these issues was essential.

*Accessibility – captioning and videos – for telemedicine to work – I've looked at the websites for telemedicine and discussion there re CI but I see no accommodation for people with HL. (U16)*

*Telehealth and online services are not accessible to the majority. Many many people do not have internet access and data is relatively expensive here [South Africa]. Open wifi (in places like public libraries) is very limited and often not working. (S18)*

*Mobile use is almost universal now – and the point was made that it needs to be available on mobiles. (U8)*

*Need to overcome the digital divide – needs to be accessible, and on phones – not everyone has laptop. (IN2)*

*Good responsiveness. New information, possibility to use them all around the word. Easy to use, so not too complicate. (U13)*

When asked about the role of the website in the survey, the most common roles were sharing resources and activity, sharing information across countries and increasing awareness, with improved expertise and knowledge.

> **The opportunity for research was mentioned, and also the importance of having it in native languages. The top two requests for inclusion were research updates and evidence and data, followed by advocacy resources and training.**

## SUMMARY

The development of CIICA and its new way of working is based on these views given in our global consultation. The responses were very consistent, even across differing groups and differing geographical areas.

CIICA will bring together the vibrant, and self-organising capacity of advocacy groups to work speedily with the need to ensure effective advocacy, working at the regional and global level.

CIICA will not replicate the many formal professional, advocacy and user/family organisations already in existence but exploit the natural synergy between them to achieve greater global impact.

**While led by users, families and advocates it will work with and call on the expertise and research of professionals and clinicians working in this field and create partnerships with their organisations.**

> "
> **Hearing loss has real health consequences and a huge economic impact on individual and society – we need to take action – we have a story to tell...**
>
> **CIICA: United by a common mission and goals to maximise access to and support for implantation…**
>
> **CIICA: a new way of working – we need to create the new landscape ourselves…**

# ACKNOWLEDGEMENTS

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