



British
Cochlear
Implant
Group

Members' Newsletter



Helen Cullington – Chair

Dear Members

We have just published data for annual numbers of cochlear implants in the UK. <https://www.bcig.org.uk/annual-uk-update/>

We ask all UK CI centres to share how many new patients they have implanted and how many existing patients they care for. This year for the first time, we also asked how many CI referrals they had each received. Last year (year ending 31 March 2021) the numbers of new patients were understandably down due to Covid-19: 848 new cases, which was around half the previous year's 1623 cases.

I am pleased to say we are definitely showing recovery now, although we are not at our pre Covid levels sadly. For the year ending 31 March 2022, the number of new people receiving cochlear implants is 1308.

Earlier this year I became obsessed (!) with mapping out how many people in the UK have received cochlear implants each year since the start! The graphs below shows the data I could find. I have collated a few sources to estimate how many new people with CI there are each year in the UK[1-4]. (I have therefore excluded sequential bilateral surgeries, as those people already had one CI.) Please note that these data are an estimate only, as some data were incomplete or conflicting, the definition of a child may have varied over the years, some centres may have included reimplantation data, some data are for calendar years and some are for financial years etc. I wasn't able to find data for some years – that is why there are some gaps in the graph.

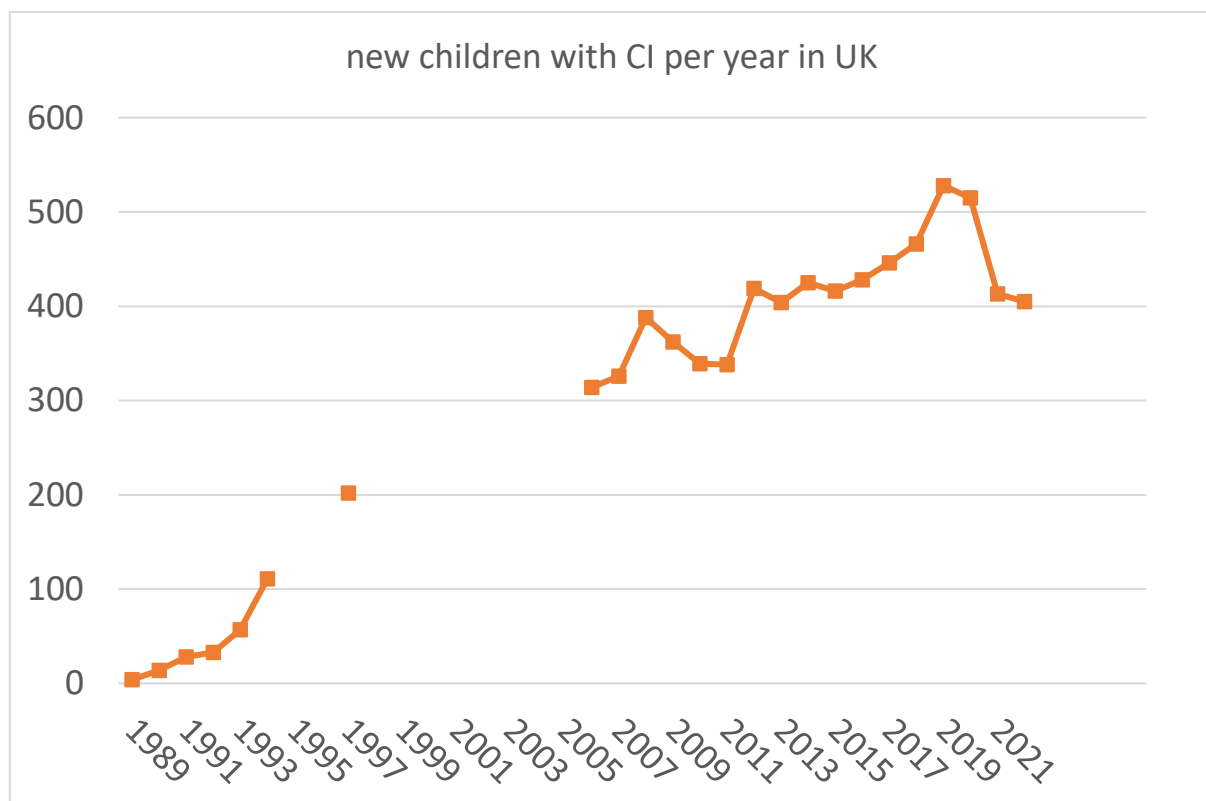
In 1992 I started training to be an audiologist. That year only around 130 people in the UK received cochlear implants. Thirty years later around ten times the number of people have received cochlear implants. And I have ten times the number of wrinkles!

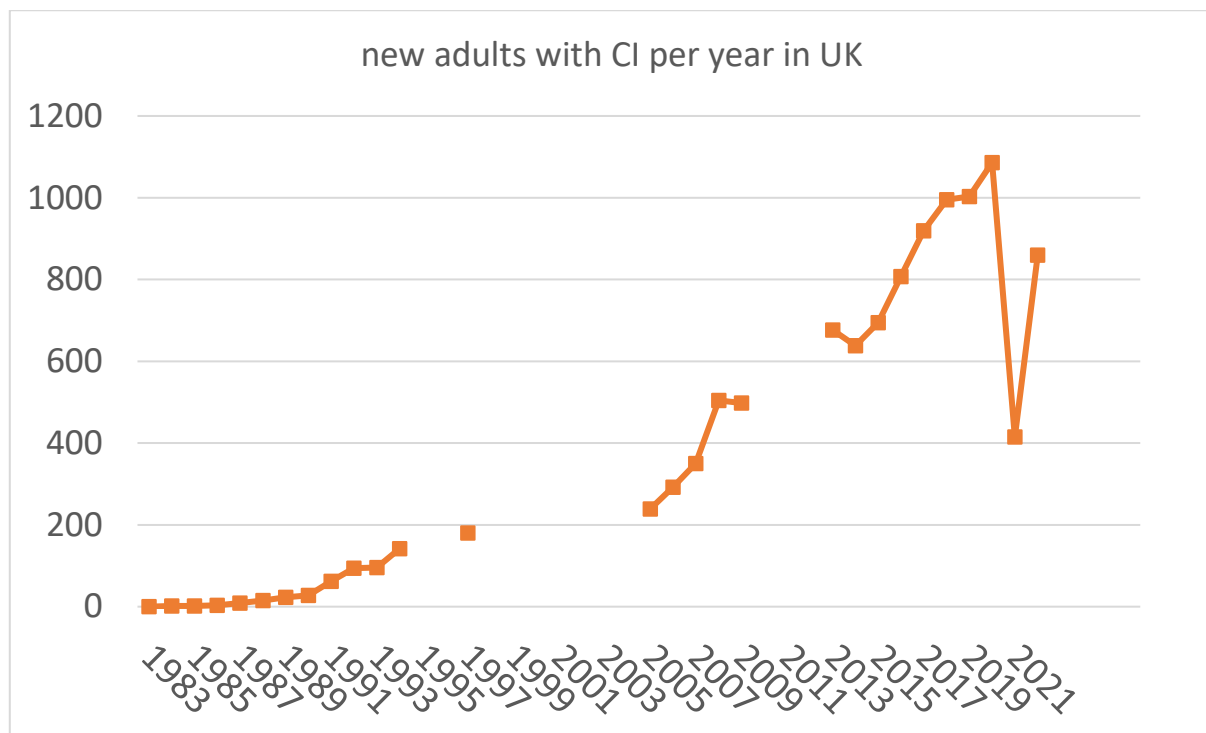


It is very encouraging to see the upward trend over the years, although this year's data shows a drop in paediatric numbers for the third year running. There are some significant events that have occurred over the years which may have impacted paediatric (and adult) numbers: the introduction of newborn hearing screening in 2001, NICE candidacy guidelines introduced in 2009 and revised in 2019, the decline in birth rates since the peak in 2012, the introduction of meningococcal vaccinations for both MenC (1999) and MenB (2015), the Covid-19 pandemic (2020 and 2021) and awareness and acceptance of cochlear implants growing every year. I would be interested in your comments on these data.

I feel grateful to live in the UK where cochlear implant surgery, equipment and lifelong care are provided free at the point of delivery to all eligible patients, and what an exciting time to spend 30 years in the field of cochlear implants!

1. Summerfield, A.Q. and D.H. Marshall, *Cochlear Implantation in the UK 1990-1994: Report by the MRC Institute of Hearing Research on the Evaluation of the National Cochlear Implant Programme : Main Report*. 1995: H.M. Stationery Office.
2. Raine, C., *Cochlear implants in the United Kingdom: awareness and utilization*. Cochlear Implants Int, 2013. **14 Suppl 1**: p. S32-7.
3. BCIG. *Annual UK update*. 2022 [cited 2022 27 September]; Available from: <https://www.bcig.org.uk/annual-uk-update/>.
4. BCIG, *Current numbers of people receiving cochlear implants in the UK*, in *British Cochlear Implant Group News*. 1998.





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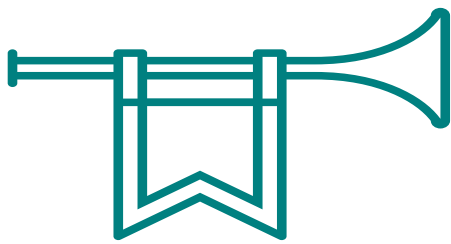
Follow **BCIG** on [TikTok](#)



Are you wearing your badge?

Would you like a few to send to your local CI Champions? There are still some available – just contact info@bcig.org.uk and Laura will arrange delivery.

Figure 1 Brilliant badges!



News from the Trustees

It's been great to welcome three new Trustees this year – Emma Stapleton, Anirvan Banerjee and Jane Gallacher.

The Trustees each have responsibilities for certain areas and, next year, we will have several openings for new BCIG Trustees.

As you know, the BCIG is a Charitable Incorporated organisation (Charity Number 1182494) with the aim of advancing knowledge, best practice, and awareness in the field of hearing implantation, in particular through the dissemination of cochlear implant research to health professionals and information to the public.

Being a BCIG Trustee is a unique opportunity to be involved in the national CI scene and contribute to the future of UK cochlear implant care. It's also a great way of getting to know your colleagues at other centres and looks great on your CV!

We usually meet six times a year – usually online these days. We are a friendly bunch and welcome people at all stages of their career.

The **maximum** length of service is six years; the initial appointment is for two years.

More detailed descriptions of what the position entails will be available on the website shortly – or contact the current incumbents for an informal chat.

Nominations will be sought early in the new year – but please start considering putting yourself forward now. It's a great opportunity to see how things work outside your specific area of expertise – and to make a difference to CI life in the UK.

Positions vacant from AGM 2023:

| | |
|---|--------------------------------|
| <i>Honorary Secretary</i> | <i>Helen Peebles</i> |
| <i>Honorary Treasurer</i> | <i>Dan Jiang</i> |
| <i>Honorary Membership Secretary</i> | <i>Katherine Wilson</i> |
| <i>Ordinary Trustee</i> | <i>Iain Bruce</i> |

Listening Effort

‘How to Measure the Unmeasurable’

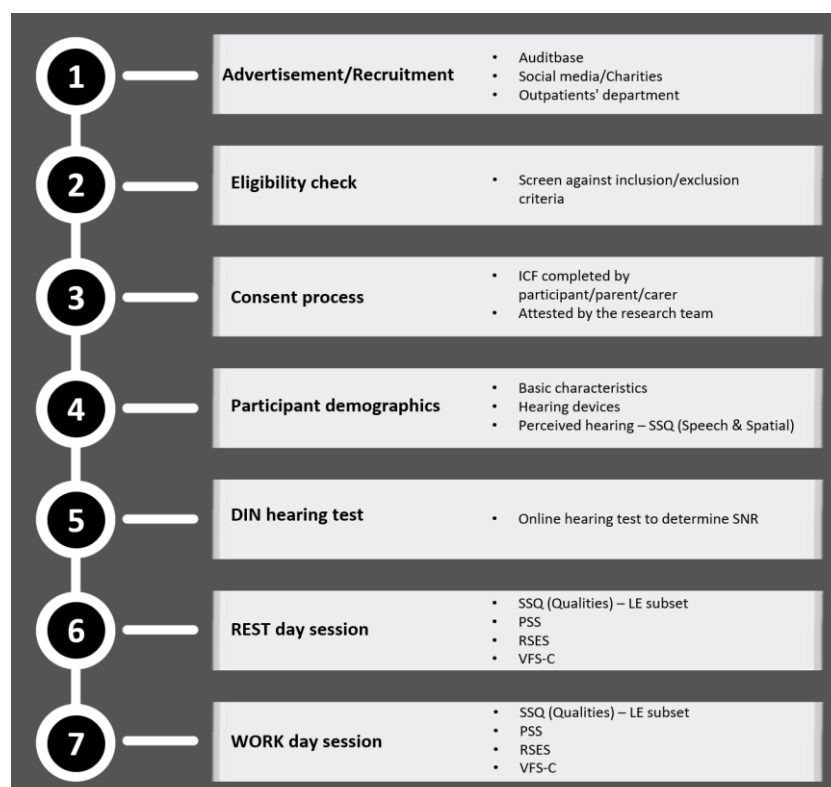
Iain Bruce, Professor of Paediatric Otolaryngology; Dr Callum Shilds, ENT trainee; Mark Sladen, Research Audiologist; Dr Karolina Kluk de-Kort, Senior Lecturer in Audiology; Jaya Nichani, Consultant Paediatric Otolaryngologist

Over the last 18 months, we have been investigating the world of ‘Listening Effort’ or, in other words, the effort which stems from processing an auditory signal. Currently, the measurement of this abstract notion is not incorporated into routine clinical practice and hence may represent an unmet disease burden of hearing loss. One of the biggest challenges to bringing listening effort into a clinical setting is the lack of consensus on measuring this construct. Across the literature, a cornucopia of tools have been postulated, examined, investigated, and championed, yet universal acceptance of a particular tool remains elusive. To delve into this topic further, we conducted a systematic review and narrative synthesis, which focused on the correlational analyses between different instruments used to measure listening effort. This review found that correlations between different instruments are often weak and insignificant, indicating that listening effort is a multidimensional construct. So, if this position is accepted, then how exactly do we measure the seemingly unmeasurable? We suggest a shift in approach to capture the downstream consequences of prolonged exposure to effortful listening, such as fatigue, stress, and low confidence, rather than listening effort itself. By utilizing pre-existing validated tools for these consequences, we may obtain a proxy measure of how listening effort affects individuals from a ‘real-world’ perspective.

To explore this further, we are about to begin recruitment for a study where we will administer these questionnaires at different timepoints to a cohort of participants with a range of hearing abilities. We will then examine the correlations between different consequences of effortful listening and listening effort itself. The protocol for this study has been submitted to BMJ open to aid the transparency of the research. Below is an outline of what will be involved.

Ultimately, if we increase understanding about the impact of varying severity of hearing loss on daily living, we will be better at decision-making about cochlear implants in those with borderline candidacy or asymmetrical hearing loss.

If you are interested in advertising this study to your patients without cochlear implants, please let us know: mark.sladen@mft.nhs.uk



BCIG 2022, Cardiff, Cymru**Being of Sound Health – the life benefits of Auditory Implants*****Rebecca Anderson***

After what was for all, a difficult few years due to the Covid-19 outbreak we were delighted to welcome everyone to Cardiff, Wales for BCIG Cymru 2022. Despite some challenges along the way including the uncertainty as to whether restrictions would be reintroduced, the conference, as a whole, was a huge success!

The conference was held in the impressive Cardiff City Hall with its majestic architecture encompassing our presenters and delegates.

As the conference began, many amongst us struggled to keep a dry eye as delegates were welcomed virtually by the Cwmbran Deaf school choir who signed and sang to “A Million Dreams”.



Over the two days of the conference, we welcomed 174 delegates, 12 company exhibitors and 29 speakers! We would like to thank all our presenters, from free paper slots to our established keynote speakers from around the globe; all of which provided us with thought-provoking content to take home to our departments. The diverse nature of our presenters allowed focussed sessions covering all major areas of our speciality. In addition to our face-to-face presenters, we exhibited a total of 82 scientific posters over the two days, showcasing the fantastic research, case studies and service developments taking place at our Auditory Implant Centres both in the UK and abroad.

A prize for the winner of the best podium presentation was awarded to Bridget Ryan for her presentation on "Cochlear hydrostatic pressures during Cochlear Implantation - A cadaveric and 3D-printed model study". The best poster prize was presented to Cillian Forde for their poster, ***"Cochlear Implant outcomes in patients with Meniere's Disease: What do impedances tell us?"***. Bridget, Cillian and all keynote speakers including Doris-Eva Bamiau, Cate Calder, Marco Caversaccio, Enrique A. Lopez-Poveda and Matthew Winn took a little piece of Wales home with them in the shape of an engraved Welsh slate trophy.

"Wide variety of talks & lots of opportunities to have discussions"

We were particularly fortunate to welcome Professor Catherine Birman as our Graham Fraser Memorial lecturer and were all in awe of the fantastic contribution that she has made to the cochlear implant profession and Otolaryngology



as a whole. Professor Birman has hosted since 2014 the Graham Fraser Memorial Fellows at her home department of the University of Sydney, Australia and I believe some of her previous fellows greatly enjoyed reminiscing at the gala dinner over a glass of wine.

"I attended as a CI Champion & really enjoyed the workshop, particularly the meeting the mentors .."

Aside from the main programme, a separate stream of content was developed for the British Academy of Audiology (BAA) and BCIG Cochlear Implant Champions. 30 CI Champions attended over the two days with the training focusing on speech testing and CI referral audit in addition to manufacturer presentations. For the first time at a BCIG Conference, we attended as a CI Champion & really enjoyed the workshop, particularly the meeting the mentors as there trialled undertaking a mock MDT that was run parallel to the main auditorium panel discussion. This was a great success with theoretical cases discussed and attendee's being provided with an insight into this decision-making process.

"Lovely to be able to network in a way that is not possible virtually"

The technology suites provided by the four manufacturers; Advanced Bionics, Cochlear, Med-El and Oticon were a fantastic opportunity to get hands on

experience with new technology and to discuss future developments and interesting cases. We would like to again thank the manufacturers for their contribution as platinum sponsors of the BCIG conference. We would also like to express our gratitude to all of our other sponsors and exhibitors.



Helen Cullington, Chair of BCIG, organised the first annual BCIG 5k run which was a huge success, attended by both keen runners and beginners to the jogging world. I am sure that this will become an annual tradition at BCIG so don't forget your trainers in 2023!

The evening celebrations began with a wonderful drinks' reception at the Cardiff National Museum and Art Gallery. Attendees were able to view the world class art with a glass of bubbles whilst listening to the beautiful calming music from a very talented pianist and CI user Elizabeth Elliot.



Our original plan of a 'silent disco' unfortunately did not come to light given difficulties with infection control following Covid-19. Ultimately this led to some acoustic difficulties in the evening with a live band in such an exquisite high-ceilinged building. Despite this following a lovely meal and a few glasses of wine, laughter and dancing was enjoyed by many and it was an opportunity for teams to come together once again following the turbulent times.



David Baguley 1961-2022

Judith Bird: The tragic passing of David Baguley has been a great sadness to his colleagues, friends, and family. Many audiologists around the globe have been influenced by him both in their clinical practice and career, benefitting both from his expertise and his kindness. Many of you will have read the moving tribute drawn together by Prof Kevin Munro. Dave's work in the field of tinnitus is widely known as this was his key area of clinical focus and research for most of his career. In addition to his notable work in the field of tinnitus, his career spanned 35 years and involved work in many other sectors of Audiology.

Dave also had a significant input to the world of hearing implants. Some colleagues across the implant world have kindly contributed some memories and reflections. His legacy continues and his absence will continue to be keenly felt.

Huw Cooper, previously head of the audiology service at QEH Birmingham and more recently area director for Cochlear U.K. before retiring reflects on some early days

David Baguley was around the same age as me, and I first knew him when we were starting out as young audiological scientists. David trained in Manchester and was always proud of his roots. I was lucky to be working for Jonathan Hazell in his tinnitus clinic at a time when working with tinnitus patients was considered to be a great challenge and not seen as a popular specialisation. David and I worked together when we were involved with the first child in the UK to receive a cochlear implant. It was an exciting time, although by today's standards the technology was very crude; it was fun to collaborate with a friend and colleague in David (see photo below).



Soon our paths diverged as he took on the challenge of moving forward the science of tinnitus habilitation, and he led the way in developing many of the techniques and key approaches now widely accepted by audiologists working with tinnitus patients. As a great collaborator, he formed strong links with many other scientists and rapidly became an internationally respected expert in the field. While building a wonderful reputation as an academic scientist, David was also a great leader and mentor to others, leading an excellent team at Cambridge which I always looked on with great admiration; he surrounded himself with great people. His kindness was brought home to me when at one point he was considering leaving audiology to become a full-time priest. He invited me, my wife Gwyn and our then toddler son to visit Cambridge. We went for a picnic, and David had thought of bringing along baby yogurts for our little one. This thoughtfulness was typical of his character.

Over the years, David grew into one of the great names in audiology but always remained a kind and caring teacher and mentor to many, mixing unbeatable academic knowledge with genuine warmth and patience. Whenever we met at conferences and meetings, he would always suggest meeting informally for a proper catch-up, and it is so sad that we can't do that now, as I would enjoy it enormously.

Bob Carlyon, Deputy Director at the Cambridge MRC Cognition and Brain Sciences Unit, has collaborated with Dave extensively over the years and describes here how Dave brought his tinnitus expertise to the field of cochlear implants.

Back in the early 1990s Patrick Axon, one of the Cambridge ENT surgeons, introduced me to a bright up-and-coming young audiologist called Dave Baguley, who combined his clinical excellence with an unbridled enthusiasm for research. This was the beginning of a long collaboration and friendship in which Dave did more than anyone to forge a strong link between basic research and clinical excellence. I soon found myself and my research team attending monthly research/clinical meetings, alongside surgical and audiological colleagues. The idea was that we would contribute our expertise to the design of clinical studies; in reality Dave was quite capable of doing that himself but it certainly proved an eye-opener for researchers used to testing high-performing cochlear-implant (CI) participants in their “steady state”, blissfully unaware of the challenges involved in surgery, fitting, and CI hardware. These meetings, combined with social outings with Dave and Patrick, led to a number of exciting projects, allowing us to obtain measurements as part of in-patient and out-patient procedures and to contribute to a clinical trial of a drug that aimed to improve hearing by CI patients.

Of course, tinnitus was never far from Dave’s mind (and always close to his heart) and I was privileged to sit in on a clinical session run by Dave for a patient with normal hearing in one ear and a CI in the other, which had been implanted in an attempt to relieve his tinnitus. The gentleman had never received counselling before and I could almost see the improvement as the session progressed (although to be fair, even I felt a lot better!). Dave and I also successfully supervised a PhD thesis on tinnitus in CI listeners, leading to the unexpected finding that 13% of CI users ranked tinnitus top of their list of concerns, with nearly a third placing it in first or second place. In all of these interactions Dave’s scientific rigour and clinical compassion shone through.

Zeb Vanat, lead Audiologist at the Emmeline Centre for Hearing Implants brings some recollections of Dave’s many years of influence on the implant team in Cambridge.

In the early days of the CI programme in Cambridge, Dave worked with Roger Gray, Ivy Court and Yu Chuen Tam with the initial intra-operative testing and implant programming. The initial programme began with the single-channel implants for adults, before progressing to the multichannel Ineraid device for the adults and the Nucleus 22 for the children.

I first met David in spring 1990 when I had my MSc. secondment for a week in the audiology department. I remember him being very kind and supportive during that week and giving me a brief update on some of the implanted patients I was to meet.

I joined the team in October 1991 and he mentored and supported me in my Certificate of Audiological Competence (CAC) for which I will remain ever grateful. Some-time after this the Audiology and Implant teams grew in size, moved apart in their physical space and were managed separately. David continued running the audiology department but still kept some involvement with the CI programme – for example, he and I worked closely for the intra-operative testing of the auditory brainstem implant. Throughout this time he continued to strengthen our team’s connections with Cambridge research teams.

For a while before moving to Nottingham, he managed both the audiology and implant teams again, helping the Emmeline Centre to become again a better integrated part of the hospital and to work more cohesively with Audiology. He played such a significant role here in Addenbrooke’s it’s really difficult to put into words – kind, caring, supportive, excellent mentor. He will be missed and I still cannot believe that he is no longer with us.



CI International Community of Action: CIICA

Increasing Access to CI and lifelong services

Sue Archbold, PhD, Hon LLD, Brian Lamb, OBE, MSc

In our first year, the CI International Community of Action's (CIICA) network has grown to over 80 organisations, and over 400 individuals from 56 countries across the globe, united in the goal of increasing access to cochlear implantation and lifelong services for all those with hearing loss who can benefit. While welcoming professional members, the majority group of our members are users, families and young people ensuring that their lived experiences are heard. Huge thanks to BCIG for being one of our founding members and hugely supportive and generous in sharing your great resources. A key issue for CIICA is to ensure not only access to cochlear implantation, but that appropriate lifelong services are available and the resources of BCIG are invaluable - and accessed globally on our website.

CIICA has come at a time when the management of hearing loss is finally starting to grow as a public health issue. The World Report on Hearing from WHO (2021) concluded that *"Cochlear Implant is one of the most successful neural prostheses developed to date"*, changing lives and opportunities. In spite of this, currently only 1 in 20 of those globally who could benefit receive this for children and adults who are deaf or have a hearing loss. This gap in provision results in a massive personal and public health issue and additional costs in dealing with the consequences of unaddressed hearing loss despite the proven benefits of CI, including cost-effectiveness for both adults and children. Even in high-income countries, access and services, particularly for adults, is fragmented. Following a global consultation, CIICA was established to tackle these important and pressing issues and the activity of the first year has been amazing.

"The synergies of the network members has far exceeded our expectations in the first year." Teresa Amat, EURO-CIU
CIICA's global community of CI advocacy groups provides opportunities to share resources, tools and activities and strengthen the user and family voice to increase access to CI's. The popular CIICA LIVE events bring together users, families and professionals globally to share their experiences on such topics as funding challenges, and advocacy work – how do we do it? Another topic has been adult rehabilitation and what is it? Too often, for adults, even in the UK, CI is provided with little follow-up.

It is inspiring to hear the innovative activities worldwide, in spite of all the challenges. Accessibility is important to us: all our events have live captioning, with translations into other languages on request. The presentations are available afterwards, with captioning. Our website has over 40 languages available and many of our resources are translated into other languages by members, and shared.

A recent innovation has been our CIICA Conversations where a small group has a conversation for one hour to explore a specific topic; these have included tele-practice, the impact of the pandemic, Re-imagining Rehabilitation and Managing Listening and Communication Effort. A summary of the issues which emerge from the Conversation is then available for further comment on the website; it's a great way to talk to other people in the same situation. A recent Conversation was about the global Living Guidelines Project which aims to provide evidence-based guidelines for adult CI and CIICA provides an opportunity to ensure the issues important to users and their families are included. See [CIICA CONVERSATION: ADULTS WITH CI TALKING ABOUT THE LIVING GUIDELINES – CIICA \(ciicanet.org\)](https://ciicanet.org) for the summary of their issues and links to the Living Guidelines Project. BCIG has been key in these Conversations and contributions to the CIICA LIVE events, providing an opportunity to share your great initiatives, such as the joint collaboration with BAA. Importantly, young people are also part of the conversations. A group of 18-30 year olds with cochlear implants, from 9 countries, met on line to have a discussion about the issues important to them on the theme of Shaping our Future Together and are planning further conversations and activities. As Bowen Tang, President of the International Federation of Hard of Hearing Young People (IFHOHYP) said: *"Our technology has to last a lifetime and we have to build a relationship with our CI"*. For many, their parents had the information about CI and it wasn't until they were adults that the young people had to take responsibility. And Bowen, implanted as a child: *because everything was taken care for me as I was growing up, I didn't develop the awareness about my implant and what I needed to do to*

be responsible for the lifetime care. Go to his contribution to the Adult Rehabilitation event: [CIICA LIVE IN NOVEMBER: ADULT CI REHABILITATION: WHAT IS NEEDED? – CIICA \(ciicanet.org\)](#) Bowen is leading our next CIICA LIVE event – 28 September 2022 – on Young People with CI : Our Challenges and Opportunities.

Our CIICA LIVE event on the impact of the pandemic was inspiring. What has it taught us and what have we learnt? The positive things we have learnt and the changes we could make going forward as well as the challenges of cutbacks in services, longer waiting lists, and the “pandemic debt”. Our global video on the impact of the pandemic on CI users, families and services is at www.ciicanet.org and you can see the captioned videos on the impact of the pandemic at [CIICA LIVE: The Impact of the Pandemic on CI users, Families and Services – CIICA \(ciicanet.org\)](#). At [THE IMPACT OF THE PANDEMIC: WHAT HAVE WE LEARNT? MEMBERS’ VOICES – CIICA \(ciicanet.org\)](#) you will see short videos of experiences of the impact of the pandemic – sharing what has been learnt globally and what we need to do.

At the time of writing, the network has been in action responding in the Ukrainian crisis to support refugees with hearing loss by providing batteries, spares and support – and showing solidarity. This year, the Ukrainian family group had achieved funding for newborn screening and for bilateral implants; they had translated the WHO materials for World Hearing Day and made videos to share. Sadly this was not to be. See www.ciicanet.org/news to see what members of the network are doing during this time.

CIICA provides a space to share resources, the tools for change which are needed: go to www.ciicanet.org/resources to find our summaries of the WHO World Report on Hearing and its implications for cochlear implant advocacy; you will also find a summary of the latest research on Hearing and Healthy Ageing. CIICA was fortunate to receive a research grant from the Social Sciences and Humanities Research Council, Canada for Adult CI users- asking them about the services they receive after CI – what are they getting and what would they like. The Survey received 1283 responses from 40 countries, an amazing response. See the first results of the responses at [Sharing initial data from our survey of adults with CI: thanks to you all! – CIICA \(ciicanet.org\)](#) : the analysis of the fascinating qualitative responses is currently underway and this research will provide a powerful report to influence future planning.

This is much needed: for example, the 2021 Eurotrak survey (www.ehima.com) showed that 69% of the German population surveyed had not heard of CI, and only 18% of those with severe/profound hearing loss had been told about CI by a medical professional. So, there is still plenty of advocacy work to be done! With the support of organisations such as BCIG, CIICA will continue to ensure that cochlear implantation remains at the front of health care decisions and that we continue to raise awareness of the impact of hearing loss and of CI.

The pandemic has made us all aware of the huge value of communication in our lives and for those with hearing loss the technology of CI can be key to communication and connection with other people. As Darja Pajk, from Slovenia said: *“maybe more people will realise the communication challenges of those with hearing loss.”*

Visit www.ciicanet.org to see our global activities and see our video about the challenges of the pandemic – and join if you want to be kept up to date, to be inspired and to contribute!

The last comment from the 18-30's was:

At the end of the day, we are all humans we all have hearts, and we all care about each other because we are all equal.
A timely word in today's world.

Any queries to info@ciicanet.org

"That is amazing, you put that thing on and you're not deaf!": Developing a long-term partnership between researchers and patients to enable lived experience to inform the research process and priorities.

A snippet of a conversation between one of our PPI members and the barber who was about to cut his hair.

Kate Hough¹, Mary Grasmeder¹, Barney Jones², Heather Parsons³, Tracey Newman⁴

1. **Auditory Implant Service, University of Southampton**
2. **Wessex Public Involvement Network**
3. **National Institute of Health and Care Research (NIHR), Research Design Service (South-Central)**
4. **Clinical and Experimental Sciences, Faculty of Medicine, University of Southampton**

The University of Southampton Auditory Implant Service (USAIS) is unique in the UK as it is embedded in the university and forms part of the main campus, just north of the city. USAIS is research active with collaborations between researchers in Medicine, Music, Engineering, Mathematics, and Social Sciences. USAIS provides care for ~2000 people with implants aged 18 months to 94 years, the majority of whom have cochlear implants. As part of our commitment to provide the highest standard of evidenced-based care and hearing outcomes, we want to continue to enhance the research activity in USAIS. On reflection, this has made us really consider how to put people with implants at the centre of what we do. To achieve this, we are developing an active and enduring Patient and Public Involvement and Engagement (PPIE) group. Patient and public involvement (PPI) describes the contribution of members of the public to the various stages of the research process, with the aim to improve the relevance and quality of the research being carried out. PPI does not mean being a participant in a research study or clinical trial, but it means contributing to and influencing the design and implementation of research studies using the unique knowledge and lived experiences of the patient or member of public. Patient and public engagement focuses on distributing the research findings and knowledge to members of the public through different activities and events.

The aim of our group is to create a partnership between patients, families, parents and carers and researchers which empowers the members of the group to contribute to, and influence, the research being carried out and to make a difference for those people with a cochlear implant and their families. Our goal is to have an established group which is ongoing regardless of the different projects that are being undertaken at the time. We aspire to establish a diverse and inclusive group, comprising of people of different ages, ethnicities, accessibility needs and backgrounds. The main drivers of this work are to increase the awareness of and access to cochlear implants and to improve outcomes for people with a cochlear implant. How can we reach the 95% of eligible people who do not have access to, or who may not be aware of, cochlear implants? And how can we improve hearing performance for those people with a cochlear implant?

We have established a vibrant patient, parent, and carer group; so far, we have 14 members. We advertised the group through social media, the USAIS website and posters in the waiting room at USAIS. Our first in-person meeting brought 8 people with cochlear implants and one partner together. Everyone introduced themselves and discussed motivations for joining the group. We discussed how the group could contribute to research and the value of everyone's unique perspective and lived experience in shaping research. The final part of the meeting let the group know about one proposed project. This initiated a discussion that gave



everyone an opportunity to ask questions and share their thoughts. Terms of reference for the group will be established over time by working with the group to discuss and decide on the key elements. These will include the role of the group, ways of working, likely time commitment, membership of the group and processes like claiming expenses. We are following the National Institute for Health and Care Research (NIHR) guidelines for paying the group members for their time, reimbursing travel costs and providing refreshments at the meetings.

Since the meeting several members of the group have been reviewing research documents for the project discussed in the initial meeting, including the ethics application, participant information sheet and the Plain English Summary. The feedback has been challenging and valuable and has already improved the information that will be submitted to secure ethical approval for the study.

Establishing and maintaining an ongoing group is challenging as it requires considerable time, effort, and funding. We have acquired the funding for this work through several successful small grant applications and we will continue to apply for further PPIE funding to maintain this group into the future. Continuous feedback, regular communication, and a growing partnership between PPIE group members and researchers is necessary for effective and rewarding involvement. Whilst creating this group, there has been an ongoing tension between the research pressures to secure funding and carry out and publish impactful research alongside taking the time to develop a group where there is a meaningful partnership between the researchers and members so the group can use their voice to truly influence research. We are hoping that by developing an authentic partnership, we can find the answers to alleviate some of this tension.

The group has multiple short- and long-term goals and aspirations. In six months from now, we hope to have expanded the group to include voices from people of all ages and walks of life with a cochlear implant, parents, or guardians of children with a cochlear implant and carers or relatives of people with a cochlear implant. We hope to have created a group where there is mutual benefit and reward for all members of the group, with researchers learning from the PPIE members and the PPIE members feeling empowered and connected through participation. In a year from now we hope to have an active group who are meeting regularly (every two to four months) and who are engaged and involved with shaping and suggesting ongoing research projects. A measure of success would be determining whether we have reduced the knowledge gap between the researchers and group members. Are we writing and communicating information about our research in a way that makes sense to the group members? In five years from now, we hope to be able to see the value of the activity through improved outcomes for people with their implants and to have a permanent PPIE lead/ research coordinator working at USAIS whose primary role is to maintain an enduring PPIE group to support the wealth of research activity at the centre. As well as supporting research activity, our goal is to establish ways to enhance and develop the service at USAIS through ongoing engagement and collaboration with the patients and carers who use the service. We are in the process of deciding a name for our group. Some suggestions include HEARAGAIN@US and AISPAC (Auditory Implant Service Patient Advisory Council). Once we have a name, you will start to see more of what our group is up to on social media – so watch this space!

Acknowledgements: A huge thank you to all the cochlear implant patients and their families and carers from University of Southampton Auditory Implant Service, who have been willing to share their time, knowledge and most importantly their personal experiences with us.

Thank you very much to Daisy Price, the artist who made the cartoon which portrays the anecdote that one of our PPI members shared with us about his experience in the barbers.

Research updates:

Datalogging findings in adult cochlear implant recipients who never developed intelligible speech

Submitted by:

Manuel Loureiro, Nishchay Mehta, Jane Bradley, Jennifer Bryant

UCL Ear Institute, London.

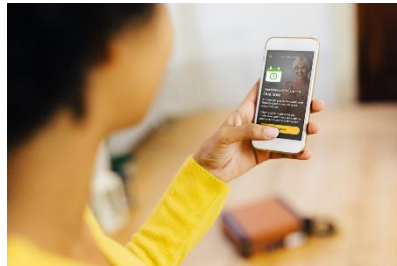
Click on the link to view poster.

Update on CIRCA (the UK Cochlear Implant Referral Criteria Audit)

Many BCIG members will have been involved with CIRCA, the project being led by INTEGRATE, the ENT Trainees Research Collaborative Network. The data collection window has now closed. Data has been received from 36 trusts covering more than 6700 patients. The team have now moved on to the data analysis stage and hope to have the manuscript written and submitted prior to the end of 2022. INTEGRATE are extremely grateful to the hard work put in by all of the BCIG members who participated. This audit would not have been anywhere near as successful without your contributions.

Chloe Swords

INTEGRATE Otology lead



Cochlear™ Remote Check – any time, any place, anywhere!

As you read this, are you old enough to remember a particular drink being advertised with the tag line ‘any time, any place, anywhere...’?

At Cochlear, we think that sounds like Remote Check! Remote Check was created to help optimise care - offering flexibility, convenience and efficiency for clinicians and patients (almost) any time, any place, anywhere.

In the post-Covid NHS context, we have heard capacity is stretched, and workloads are heavy. Patient numbers are increasing, and all require high standards of lifelong care¹. You may remember our ‘Get Connected’ focus at the recent BCIG conference, highlighting the increasing importance of enabling patients to be connected and to access remote care options. Remote Check is one of our Connected Care services. It is intended to help clinics manage their patients efficiently, without compromising on the quality of care, by enabling cochlear implant patients to complete a hearing health check at a convenient time and place, without visiting the clinic.

Recently, Nottingham Auditory Implant Programme², and The Midlands Hearing Implant Programme- Children’s Service³ looked at the impact of Remote Check on their practice. These experiences have been written up as case studies (to read the full reports click on [Nottingham](#) or [Midlands-Paediatric](#)). In addition, over 100 patients from around the UK have been surveyed about their experience using Remote Check⁴. Here are some of the take-away findings:

Survey of over 100 patients:

9/10 patients would recommend Remote Check to another person in their situation.

97% of respondents felt very or somewhat confident to complete their hearing check remotely.

92% said they would be likely/very likely to do another Remote Check, if offered by their clinic.

“Ease and convenience of use, reassuring and extremely straightforward.” – Andrew D.

“Very easy to do and clinicians could see the results” – Samantha W.

The studies found Remote Check can help to:

- Release clinical time for complex programming and pre-implant assessments
- Reduce waiting times
- Improve access to care
- Improve patient satisfaction
- Drive digital transformation

For further information on establishing Remote Check in your clinic, please contact your Cochlear Business Manager.
Cochlear UK +441932263637

<https://www.cochlear.com/uk/en/professionals/connected-care>

References

¹<https://www.bcig.org.uk/wp-content/uploads/2021/08/2-8-21-BCIG-CI-data.pdf>

²Nottingham Case Study: D1933487 V2 2022-05

Kim Veekmans, Clinical Scientist* Susan Johnson, Audiology Lead and Deputy Head of Service

³Midlands- Paediatric Case Study: D1943853 V2 2022-05

Justine Maggs, Principal Clinical Scientist – Audiology, Sadia Zoolfqr, Specialist Paediatric Audiologist, Marett Ambler, Principal Clinical Scientist – Audiology, Hannah Ager, Principal Speech and Language Therapist, Kate Hanvey, Head of Department, Principal Speech and Language Therapist

⁴Source: Survey conducted by Cochlear on 102 recipients in January 2022.



Meet your AB support and community team:



Yvonne Noon
Support & Community
Specialist



Shahad Howe
Support & Community
Specialist



Nicole Da Rocha
Support & Community
Specialist

We recently introduced our Business Development Team in our Summer Professional Newsletter. We have now updated our name to better reflect the support we offer to professionals, candidates, recipients and their families. Some of the ways we can support you and the families under your care are:

AB Community

Our community of volunteers and mentors is ever-growing and we have recently welcomed a number of Parent Mentors to the group to help support families and caregivers at the start of the cochlear implant journey. If you have a family in need of support from those who have been through the journey, please reach out to us.

Audiology and Education Support

We continue to work with CI Champions, Audiology referrers and Education teams to raise awareness about cochlear implants and encourage early referrals. If you feel your local teams would benefit from a cochlear implant and rehabilitation update, please let us know.

Communicate with Success Events

We host bi-monthly virtual group events where we focus on a theme that may interest both professionals and those living with hearing loss. These can include technical updates, rehabilitation resources, cochlear implant awareness and collaboration with hearing charities. Look out for upcoming dates on our events page: www.advancedbionics.com/uk-events

Communicate with Success 1:1 Support

We offer 1:1 support sessions for anyone considering a cochlear implant or anyone who already has an AB CI. These can be virtual or in-person sessions and can cover anything from finding out more about cochlear implants and AB technology, to learning how to get the most out of AB technology. We offer advice on accessories, wireless connectivity, and troubleshooting. Anyone can register for a 1:1 support session via this link: www.AdvancedBionics.com/CWS121

We understand the pressures you are working under and are here to support you. If you would like to talk to one of our Support & Community Specialists, please get in touch at hear-uk@advancedbionics.com



Bimodal Hearing with a Cochlear Implant and a Hearing Aid



At MED-EL, our unique approach means that our cochlear implants are a great match for any hearing aid used with the contralateral ear, but we don't stop there: With the AudioStream accessory, users can stream sound to both ears (bimodal streaming).

<https://www.medel.com/hearingsolutions/accessories/connectivity/audiostream>

Made for Bimodal Hearing

Other implant systems are often promoted as having a specific partner-brand hearing aid. These systems are marketed as better because that aid can be programmed to process some aspects of sound in a similar way to that implant. However, with these other systems, this usually means significantly changing the way the aid treats sound.

Pitch Match

Most importantly for bimodal listening, with MED-EL using long electrodes and FineHearing sound coding, the sounds from the cochlear implant and the hearing aid can be closely matched in pitch. Providing a full, matched range of frequencies across both ears can make it easier for the brain to combine and compare the sounds from both ears.

Other cochlear implants are not designed to use the whole cochlea. For bimodal listening, these systems use "partial integration", which may lead to unbalanced signals between ears that may offer the brain less information.

Loudness Growth

Our processors are designed to provide a close match to natural loudness, with relatively 'gentle' compression, a better match to typically used hearing aid compression.

Our cochlear implants are designed for use with any hearing aid without compromise! For more information, please visit our website <https://www.medel.pro/systems/cochlear-implant-system>

BCIG Annual Conference in Cambridge 2023

13th – 14th April 2023



“Current Challenges and Opportunities in CI”

Abstract Submission is OPEN.

The British Cochlear Implant Group welcomes free papers in both oral and poster format.

SUBMISSION DEADLINE - SUNDAY 22ND JANUARY 2023

Abstract topics:

- *Audiology*
- *Paediatric rehabilitation*
- *Adult rehabilitation*
- *Surgery and clinical*
- *Basic / Translational science*
- *Other*

Please note this is a strict deadline in order to allow selection by the academic committee with sufficient time for the successful candidates to book appropriate study leave.

Abstracts relating to our conference theme will be viewed more favourably.

For more information and to submit an abstract - <https://bcig2023.exordo.com/>

I'm Deaf, my daughter is profoundly Deaf and wears bilateral cochlear implants and I'm also a Teacher of the Deaf!

I have just come across your website and just wanted to say how informative it is, Thankyou!

The new BCIG website will be launched soon! The aim is to make it even more user-friendly and the Go-To website for everyone in the CI community.

