



Anna Tucker

Involving and Engaging Patients and the Public

The British Cochlear Implant Group (BCIG) last year initiated a Patient and Public Involvement and Engagement (PPIE) group to enhance the quality and impact of their work. PPIE is essentially, in the words of the National Institute of Health Research, about ensuring research and activity “is carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”.

The aim of the BCIG PPIE group is to ensure cochlear implant users and their families/carers inform BCIG projects with lived experience - providing their own unique insight to influence the direction of future projects and be a resource for national researchers and policy makers.

The PPIE Group is made up of cochlear implant users and parents/carers of children with cochlear implants and is co-ordinated by Anna Tucker, herself a bilateral implant user.

The initial brief for the PPIE group suggested by BCIG chair Professor Manohar Bance is to address:

- roadblocks to cochlear implant uptake
- troubleshooting cochlear implant performance
- the usability and design of cochlear implant processors
- screening and testing hearing loss for cochlear implant candidacy
- speech and language development for children and adults using cochlear implants
- the testing of new technologies
- supporting research projects

The group was initially set up on a somewhat ad hoc basis and has recently embarked on a discussion of how best to formalise its objectives and terms of reference, widen its membership and broaden involvement. To this end it is currently, with strong support from Manohar and his colleagues, engaged in mapping the range of existing user and support groups, networks and organizations to try (1) to ensure that their voices (from the National Cochlear Implant Users Association, the Cochlear Implanted Children’s Support Group to smaller local groups) are more effectively heard, and their members informed and involved in activities and research and (2) to broaden BCIG and its members’ pool of experience and knowledge.

The current group has already been involved in such activity as

- commenting on new leaflet publications for users, research proposals and questionnaires

- providing user panel representation at the 2023 BCIG conference
- giving some initial feedback on plans for developing the NHS National Registry of Hearing Implants
- contributing to an audio presentation about cochlear implants for the 2023 British Academy of Audiology annual conference
- producing a briefing for BCIG on the most pressing issues for cochlear implant users - see the PPIE section on the BCIG website

BCIG PPIE Group meetings are held online with regular contact between members by email and a WhatsApp group on current projects and discussions.

Group member Steven Kennedy, who had a cochlear implant two years ago at AIS, Southampton says “Had I not had my implant I would now be almost entirely unable to participate in conversations at all. My implant has transformed my life and it is great to be able to give something back by working with a group of like-minded people to try and broaden access and eligibility and improve CI users’ experience and support.’

Tricia Kemp, Group Coordinator of the Cochlear Implanted Children’s Support Group (CICS) and Vice Chair of the NCIUA says ‘Cochlear implants are proven to be safe and effective and are enabling deaf children and adults to have much greater access to the hearing world than ever before. However, we must not be complacent. There is more to be done in raising awareness of cochlear implants and to ensure that deaf people of all ages have equal access to the technology and are well supported throughout their journey. In considering future practices and policies regarding all aspects of cochlear implants it is vital that the voices and views of cochlear implant users of all ages and their families/carers are heard, listened to and acted upon.’

June Statham, a researcher from Wales, says: ‘I was so pleased that I could hear words as soon as my implant was switched on, but I know people’s experiences vary and I would like to support research and development to improve outcomes for CI users’.

If you would like more information about the BCIG PPIE Group, are interested in participating or involving the Group in research, please email Anna Tucker, annatucker@ci-conversations.co.uk



British Cochlear Implant Group

Patient and Public Involvement and Engagement Group

