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Our website: <https://generic.wordpress.soton.ac.uk/all-ears/>

ALL_EARS@UoS is a patient and public involvement and engagement (PPIE) group for people with lived experience of hearing loss. Our group was set up by researchers (Prof Tracey Newman and Dr Kate Hough) at the University of Southampton and started recruiting in March 2022. We now have 48 active members, and our membership currently includes deaf and hard of hearing people, family members, carers, health professionals and researchers.

The name 'All Ears' devised by a group member, encapsulates what our group is all about. Everyone who is interested regardless of their background has a part to play, young or old, in work or retired, from any background who has an interest - is invited to participate.

When we set out, our key drivers were to 1. Increase awareness of hearing loss and cochlear implants and improve access to cochlear implants and to 2. Improve outcomes for people with hearing loss by embedding lived experience into our research. Over time, researchers and members of the group have worked together to co-develop all aspects of the group including the name, logo, aims, ethos and objectives and ways to working.

'I've been losing my hearing for 20 + years and this is the first time anyone has asked me for my opinion. It genuinely feels like we're listened to, and our comments are valued and appreciated. It feels like the group is building momentum, and going forward has the capacity to have an impact and make a difference'.

We are expected to be engaged. There are many ways we can get involved and contribute. We can share what we learn about hearing and brain health, hearing aids and cochlear implants with our communities; be it family and friends, community and social clubs and prospective hearing aid or cochlear implant users. We can raise issues that affect us or our communities so that professionals know what matters to us, such as how to get hearing tests and what are assistive listening devices i.e. loop systems. We may be asked to spread the word about research projects to encourage others to take part i.e. by completing a questionnaire.

We are often invited to help run exhibits at events such as at the annual University of Southampton Science and Engineering Festival. It is a real privilege to be able to use our lived experience to support others along the road.

'Encouragement to speak out and listen, using my implant to its full ability. The confidence to participate in discussions after many years of being mostly excluded from conversation'.



Sometimes we can be asked our views on practical issues. For example, a group of us were invited to a discussion before work on a new music app, for people with cochlear implants, got underway. We have also provided feedback and shared ideas for how communication can be improved between clinicians and older adults at the University of Southampton Auditory Implant Service.

We often have the opportunity to be involved further in the research process. For example, using lived experience to comment on plain english summaries or to comment on the ethics application for a project before submission, or even suggest topics for research.

Each year there is an evaluation questionnaire which, as members of the group, we should respond to saying what we feel has gone well and what needs improvement so we can truly be 'All Ears' a Patient, Public and Researcher collaboration.

The group has grown and developed hugely since the group's first meeting in May 2022. Through going out into the local community and building trust with community members over time, we have increased and broadened the membership of the group so that now it better reflects the diversity of the d/Deaf and hard of hearing community and our local community.



There are challenges in running and maintaining an enduring PPIE group which should be considered from the early stages of building a group. For researchers, a key challenge is the amount of time, funding and resources that are required to sustain the group. Funding is required to ensure our meetings are fully accessible with an electronic notetaker and interpreter if necessary. In addition, funding is required for staff time, to reimburse group members for their time and travel expenses and to provide refreshments at meetings.

For public involvement and engagement to be effective, the group should reflect the diversity of our communities. We have worked hard to increase the inclusivity and diversity of our group by going out in our local community, building trust and encouraging involvement in our group. Community engagement takes considerable time and resources too. Researchers working with us have to continually apply for grants to ensure a regular funding stream.

Through our evaluation, we are aware of the challenges that exist for our group members. This includes the accessibility of the meetings including time of day and meeting format, as well as being involved alongside other commitments including employment and caring responsibilities.

Despite the challenges, the partnership we have built between researchers and members of the public has resulted in a whole host of valuable outputs and outcomes. We've had input to ten research projects and five grant applications. We've taken part in six public engagement events to raise awareness to members of the public. At one event, 88 visitors were able to check their hearing using the RNID hearing checker. We have one co-written blog and presentation and two co-developed publications – one of which is published in the British Medical Journal where we outlined key deaf awareness strategies to improve communication (<https://www.bmj.com/content/386/bmj.g1438>).

We encourage researchers and members of the global D/deaf and hard of hearing community to come together and work together as the opportunities to raise awareness, learn new things and enhance hearing research, are endless.

