

Priority Setting Partnership for Childhood Deafness and Hearing Loss: Children and adults with lived experience deciding what future research needs to focus on

Hannah J Stewart¹, El Smith¹, Anisa Visram², Jenny Chan², Amanda Hall³, and Juliet Viney⁴

¹Psychology, Lancaster University, Lancaster, LA1 4YW

²Manchester Centre for Audiology and Deafness, University of Manchester, M13 9PL, UK.

³Department of Audiology, School of Life and Health Sciences, Aston University, Birmingham B4 7ET, UK

⁴Parent Partner

The Childhood Deafness and Hearing Loss Priority Setting Partnership (PSP) was launched in November 2023. The project is led by the University of Manchester in conjunction with researchers from Aston University, Lancaster University and the National Deaf Children's Society. Together with our committed steering group of people with lived experience, we aim to bridge the gap between what researchers want to research, and what children, caregivers, and relevant professionals want to know.

Following the well-established James Lind Alliance PSP methodology we are gathering evidence from across the UK to compile a 'Top Ten' of the most important questions researchers should be trying to answer about childhood deafness and hearing loss. The goal of a PSP is to ensure that those funding health research understand and consider the priorities of the people who will benefit from it.

Our PSP is currently in phase 2: Collecting initial priority questions via surveys for adults, young people and children. In just a few minutes you can anonymously tell us what *you* think the research priorities in childhood deafness are. Equally important, please share this opportunity with children, young people and families affected by childhood deafness and your colleagues, from all disciplines. Access to the survey: <https://www.ndcs.org.uk/research-priorities>

We are also running activity-based focus groups, led by the team at Lancaster University with expert facilitators to encourage children (7-11 years old) and young people (12-16 years old) with hearing loss to be able to express themselves fully and share what is important to them. If you know families who would like to take part (expenses paid), please get in touch with the focus group team (pelican@lancaster.ac.uk). We are travelling the UK and are in Lancaster on the 22nd of June; Edinburgh on the 29th of June and Bristol on the 12th/13th of July.

