

Top 10 research priorities on childhood deafness and hearing loss: developed by children, families and professionals

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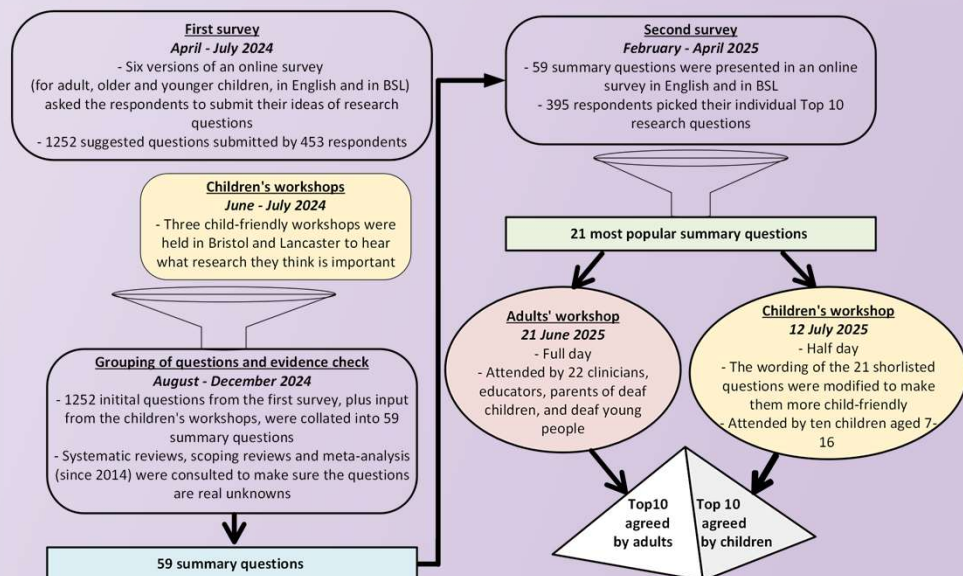
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Background

- ❖ The James Lind Alliance (JLA) brings patients, carers and clinicians together in JLA Priority Setting Partnerships (PSPs). PSPs use a well-defined and transparent process to identify and prioritise unanswered questions in the topic chosen.
- ❖ Permanent childhood hearing loss affects around 2.2 in 1000 children at birth¹. The prevalence rate increases with age during childhood, due to later acquired and progressive hearing loss².
- ❖ In June 2023, a PSP in Childhood Deafness and Hearing Loss was registered with the JLA, and the whole process of identifying the Top 10 research priorities was launched.
- ❖ In this PSP, the term 'deaf' refers to all types and degrees of hearing loss. This includes deafness in one ear or temporary hearing loss such as glue ear.

Methods



Top 10 priorities agreed by parents/carers, young persons and professionals

1	What are the best ways to support the special educational needs of deaf children, including children with multiple special education needs, to improve educational outcomes; what support is being provided currently in different school settings, and how effective is it?
2	How can deaf children be empowered to advocate for themselves, understand their deafness, develop confidence and independence, and be prepared for adulthood?
3	How can families be supported to build positive relationships and communicate well with their deaf child, and how does this affect language, cognition and social-emotional development?
4	What is the impact of mild deafness or unilateral deafness on the outcomes of children and young people, and do hearing technology and educational interventions help?
5	How can deaf children develop a positive Deaf identity/sense of self, feel accepted in both the Deaf and hearing communities, and what is the impact of Deaf culture and role models?
6	How can language deprivation be identified early, what are its impacts, and what interventions can help?
7	What are the availability, barriers and enablers to learning and using British Sign Language (BSL) for deaf children of all ages, their families and professionals across the UK?
8	How do communication choices, like British Sign Language (BSL), spoken language, or a combination of both, affect deaf children's mental health, education, and well-being, and how can this be communicated to families to ensure informed choice(s)?
9	What are the causes, prevalence and impact of glue ear, and which interventions and clinical pathways are most effective in supporting families and improving outcomes?
10	Which interventions are the most effective in developing speech and/or language skills in deaf children?

Top 10 priorities agreed by deaf children

1	How does it affect deaf children when they miss out on hearing things going on around them? Like during play with their friends.
2	How can families communicate well and have a good relationship with their deaf child?
3	What kinds of help do deaf children need at school, especially if they have other learning needs too? Are they getting this?
4	If a child is a little bit deaf or deaf in one ear, do they still need help? If so, what works?
5	Is it harder for deaf children if they don't learn to communicate early in their lives?
6	What needs to happen to help deaf children make and keep good friends?
7	How can we tell what sort of schools are best for deaf children? e.g. a school with just deaf children, a school with deaf and hearing children, or a school with a special team to help deaf children?
8	How does being deaf change the way children think, learn, pay attention, understand other people's feelings, and feel sensations in their body? What would help?
9	Is speech and language therapy helpful for deaf children?
10	What might help a deaf child feel proud and more confident about growing up to be a deaf adult?

The questions that are highlighted in colour appear both in the adult and the children's Top 10. Those that are not highlighted are unique in their own list.

References

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Conclusions and future directions

- A UK-wide collaboration with deaf children and adults with lived experience was established to reach consensus on the research priorities in childhood deafness.
- With the 'Top 10' research priorities identified, we will work with different stakeholders to help shape these into research projects; and to engage funders, policymakers, and researchers in addressing these research gaps.
- A new legacy group, the Childhood Deafness Research Network, was formed following the completion of the JLA exercise to optimise future opportunities for collaboration among different stakeholders. Learn more and join us at <https://childdeafnessresearch.co.uk/>

