

Research Priorities in Childhood Deafness and Hearing Loss

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Summary

Our group followed the James Lind Alliance (JLA) priority setting partnership (PSP) methodology to define the top 10 research priorities in Childhood Deafness and Hearing Loss. This was a **hugely collaborative** project, and we expanded our initial project team and funding to include Lancaster University researchers bringing additional funding and expertise to allow us to include children's focus groups and a final children's workshop in the process. We are **the first JLA to run a children's final workshop to generate a child-specific top 10**, and other JLAs have been getting in touch to learn from us. The top 10 lists included a **variety of topic areas covering education, wellbeing, audiological/medical, communication, services, and intervention/outcomes**. Participation was **diverse and widespread** giving us confidence that these research priorities truly represent what matters most to people. We have established a **legacy group, the Childhood Deafness Research Network**, to promote our findings and work towards answering the identified priority research questions. Our website has been **accessed over 3,000 times**, and tells the story of our project, highlighting the Top 10 lists, and giving access to various dissemination materials <https://childdeafnessresearch.co.uk/>.

Acknowledgements

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NDCS acted as a key partner organisation with particular support in communications to improve stakeholder engagement. Thanks to all partner organisations (Appendix C) for their support. Thanks to all steering group members for their ongoing dedication and insight. Thanks to our expert reference group for their support and promotion of the project. Thanks to all children and adult stakeholders who contributed to any or all stages of the engagement project – your insights are what this work is all about and what we present here.

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Introduction

Aims and key elements of JLA process

The broad aim was to follow the JLA PSP process to define the Top 10 research priorities in childhood deafness. Key elements of the JLA process include: giving equal voice to professionals and people with lived experience, sampling a diverse and representative range of stakeholders, working with a steering group made up of similarly representative stakeholders to guide decision-making throughout the process, and ensuring transparency of methodology and data at all stages. A further guiding principle is that researchers (without a clinical role), funding bodies, and industry do not form part of the stakeholder group who are consulted. This is to avoid bias and ensure the Top 10 list represents the experiences of those with daily experience of childhood deafness or of caring for deaf children.

Purpose and ongoing funding opportunities

As well as letting researchers know what matters most to those affected by the conditions studied, JLA PSPs can influence funding, specifically when appropriate follow-up work is carried out in terms of dissemination and project development (Staley *et al.*, 2020). As an example, the National Institute for Health and Care Research (NIHR, the largest funder of health and social care research in the UK) has a rolling funding opportunity for research addressing priorities identified by JLA PSPs, which runs across multiple NIHR programmes (NIHR, 2025). Successful hearing-related PSPs have been run on the topics of tinnitus, mild-moderate hearing loss, and hyperacusis. News from the tinnitus JLA demonstrates the wealth and breadth of research that followed the publication of their top 10 list (JLA, 2017). The narrowing attainment gap between deaf children and their normally-hearing peers in recent years is evidence that we can make a real difference to children's lives with the right information and resources to support the care we provide (Hutchinson, 2023). The fact that such a gap remains demonstrates that we still have work to do.

Findings

Table 1 shows the Top 10 research priorities list according to adult stakeholders. The "themes" were allocated to questions during the phase in which the summary questions were collated from the initial data collected from the online survey (see methodology). All themes were represented in the adult Top 10 apart from "interventions and outcomes" (which was represented in the children's list), demonstrating a good diversity of priorities in the final lists. Note that the text in bold was not part of the original question. This has been included to clearly show the main topic of each question, and for easy comparison between the adult and children's lists.

Table 1: Top 10 priorities according to adult stakeholders.

#	Priority	Theme	Child #
1	Special educational needs: 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?	Education	3
2	Self-advocacy: How can deaf children be empowered to advocate for themselves, understand their deafness, develop confidence and independence, and be prepared for adulthood?	Wellbeing	10
3	Family relationships: 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?	Wellbeing	2
4	Mild and unilateral deafness: 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?	Audiological / Medical	4
5	Deaf identity: 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?	Wellbeing	n/a
6	Language deprivation: How can language deprivation be identified early, what are its impacts, and what interventions can help?	Communication	5
7	Access to learning BSL: 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?	Services	n/a
8	Communication choices: 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)?	Communication	n/a
9	Glue ear: 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?	Audiological / Medical	n/a
10	Speech and language interventions: Which interventions are the most effective in developing speech and/or language skills in deaf children?	Communication	n/a

Table 2: Top 10 priorities according to deaf children

#	Priority	Theme	Adult #
1	Incidental hearing and learning: How does it affect deaf children when they miss out on hearing things going on around them? Like during play with their friends.	Interventions and outcomes	n/a
2	Family relationships: How can families communicate well and have a good relationship with their deaf child?	Wellbeing	3
3	Special educational needs: What kinds of help do deaf children need at school, especially if they have other learning needs too? Are they getting this?	Education	1
4	Mild and unilateral deafness: If a child is a little bit deaf or deaf in one ear, do they still need help? If so, what works?	Audiological / Medical	4
5	Language deprivation: Is it harder for deaf children if they don't learn to communicate early in their lives?	Communication	6
6	Friendships: What needs to happen to help deaf children make and keep good friends?	Wellbeing	n/a
7	Type of school: 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?	Education	n/a
8	Cognition: 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?	Audiological / Medical	n/a
9	Speech and language therapy: Is speech and language therapy helpful for deaf children?	Communication	n/a
10	Self-advocacy: What might help a deaf child feel proud and more confident about growing up to be a deaf adult?	Wellbeing	2

Table 2 shows the Top 10 research priorities as they were ranked by the deaf children participating in the children's final workshop. These questions are presented using the child-friendly language that was used during the children's workshop.

All workshop participants reported thoroughly positive experiences of taking part in the workshops. All participants got involved in the discussions, listened with respect, and a mutually agreed consensus was reached that all were happy with. Participants noted that **all 21** questions which were discussed in the workshops were important areas for research. The adult workshop methodology meant that all 21 questions were ranked. Appendix A shows how adults ranked the remaining 11 questions from their workshop.

Discussion and Suggestions

Diversity and representation

During our data collection we made use of ongoing analytics to monitor the demographics of those contributing to our surveys whilst these were active. This was a very valuable exercise as it gave us a point of discussion in our steering group meetings to see which groups we needed to make efforts to reach out to. During the course of the surveys, the under-represented groups included: people from Wales, those from non-white ethnic backgrounds, and men. This allowed us to make targeted efforts to reach these groups and reduce the discrepancies. This led to a significant improvement in the proportion of responses from Wales, marginal improvement in the proportion of responses from non-white populations, and negligible improvements in the number of responses from men. Overall we were very pleased with the diversity and representation, though certain discrepancies remain.

Whilst there is a large discrepancy in terms of gender, this is un concerning for the professional respondents in whom there is a known population gender discrepancy. It is unfortunate that we were not able to reach more fathers and male deaf children and young people. However, previous experience shows this is an expected if unfortunate finding (e.g. Phares *et al.*, 2005). Our group have various projects in place to look at how to reach more diverse contributors and research participants, and 'men' represent one of the groups we are targeting. Strategies to increase participation from fathers have been reported (Davison *et al.*, 2017) representing a useful starting point to reach out to this group. An over-representation of white ethnicities remained, though this did reduce over time. Further demographic information about survey participants is presented in Appendix B.

Monitoring the number of responses to the surveys in real time allowed us to observe which marketing methods were most effective. The NDCS mailing list was by far the most effective method of promoting the survey, and we are very happy to have been working with the NDCS communications team to make this possible.

The steering group is a vital component of all JLA PSPs – a representative group of professionals, patients and carers that guide decision-making throughout the project. Information about the composition of the steering group is found in Figure 1 in the methodology section. The steering group discussed and refined its own composition (for example agreeing that representation from a Deaf professional was important). Hence the group achieved an excellent and well-considered representation from a wide range of professionals and those with varied lived experiences.

Learning points around hearing children's voices

Whilst we struggled to recruit children to take part in the surveys, we suspected in advance that this was not the ideal method of hearing from children, and hence ran focus groups to ensure their voices were heard (made possible by additional funding from Research England's QR Participatory Research Fund to Lancaster University, and UKRI Future Leaders Fellowship MR/X035999/1 to Hannah Stewart). The focus groups acted as a test bed for adapted methodologies for the final children's workshop. These methods of engaging children were a great and unique strength of our PSP.

"I learnt that my voice matters and I can make a difference for me and other deaf children" (quote from participant in children's workshop)

The importance of hearing children's voices was echoed repeatedly from the children themselves, the parents, the steering group, the legacy group, and the interest from the JLA itself and other PSPs. At the start of the project it was not known how well the children would be able to empathise in order to rank the research priorities according to what was important to all children and not just themselves. In reality, the adapted workshop techniques meant children were able to do this very well. As an example of the adapted techniques, deaf illustrator Emma Clements was commissioned to create specific illustrations (a selection shown below) that were used to represent a range of characters. Children in the workshop could choose and build up stories of the characters' experiences, share their characters with each other and hence get a deeper appreciation of the factors that might impact a range of individuals beyond themselves.



Value of the steering group and collaborative working

Having a diverse and dedicated steering group, including a parent co-applicant on our management group (the team leading the work), made the project wonderfully collaborative and rewarding for all involved. As well as guiding decision-making during monthly meetings, the steering group successfully participated in data analysis. Subgroups were formed to work on specific 'themes' of questions when producing the first list of summary questions (see methodology). A face-to-face meeting was held to bring the group together to debate and finalise the summary questions. This was a very efficient and worthwhile way of working, allowing us to come to swift and collaborative decisions about the final summary questions list. Further subgroups helped to work through the evidence-checking stage, checking existing literature for up-to-date systematic reviews, scoping reviews and meta-analysis relevant to our summary questions.

We also worked with researchers across three academic institutions to complete the PSP: the University of Manchester, Aston University, and Lancaster University. This has also been a very useful and enjoyable collaboration and has helped to ensure reach and diversity in the wider groups we have engaged in the PSP.

Addressing the research priorities: legacy group

Following up the JLA PSP with tangible actions, such as promoting the priorities and designing studies to address the questions, is key to ensuring the hard work of this project is not wasted and results in actual benefits for deaf children (Staley *et al.*, 2020). It is furthermore important to hold a clear line of sight between priorities, research, and practice to enable meaningful change. At the time of writing, our legacy group, the Childhood Deafness Research Network, has had its inaugural meeting, during which the group decided on our immediate priorities. The initial priority was agreed to be dissemination of the Top 10 (see following section). We therefore intend to have a period of intense dissemination over the first quarter of 2026, so as not to lose momentum and to also be able to move on to the important wider aspects of follow-up work. Our secondary priorities are: to provide Patient and Public Involvement and Engagement support and professional mentorship to others developing research projects related to childhood deafness, and to maintain our outstanding work in representing children's voices throughout the project. A longer-term goal is for the group itself to develop a and run a research study related to the Top 10 priorities.



Information about the legacy group (open for other professional and lived experience members to join), the JLA process, and the Top 10 lists is found on our website: childdeafnessresearch.co.uk

Dissemination

Dissemination activities are summarised below.

Publications

Academic journals

- Correspondence letter submitted to the Lancet in January 2026 but was not accepted. We are in the process of rewriting the submission for BMJ Paediatrics Open.
- Peer-reviewed journal articles in preparation highlighting the child-specific data and activities carried out

Professional / non-academic magazines

- BATOD magazine article submitted
- Members of the steering group and childhood deafness research network will author publications to magazines in their area of expertise/influence including (but not limited to):
 - Audacity (British Society of Audiology)

- BAA News (British Academy of Audiology)
- ENT & Audiology News
- NDCS Connect

Promotional materials

We have produced a booklet, flyer, posters, and website to promote the Top 10. The printed materials are also downloadable from the website. We also intend to produce an easy-read version of the booklet and have prepared an initial draft of this. Booklets and flyers have been taken to conferences and other professional meetings, with a copy of the flyer being included in delegate bags at the BAA conference. Posters will be posted out to deaf schools and paediatric audiology clinics.

Oral/poster conference presentations (completed)

- International Congress on the Education of the Deaf, 2025
- British Academy of Audiology, 2025
- Asia Pacific International Conference on Speech, Language, and Hearing, 2025

Oral conference presentation (upcoming)

- World Congress of Audiology, 2026

Presentations to other meetings

- Northwest Paediatric Audiology Clinical Network meeting, July 2025
- The University of Manchester Division of Psychology, Communication and Human Neuroscience Research Showcase, October 2025
- NIHR Manchester Biomedical Research Centre Children's Research Discovery Day, November 2025

Steering group, expert reference group, partner organisations, and press

Dissemination has also been carried out via personal and professional networks of those involved in the project, including the steering group, expert reference group, partner organisations (see Appendix C), and NDCS. The methods of dissemination have included contacts via social media and email lists. A bespoke 'carousel' was designed for social media dissemination. A joint press release was agreed between NDCS, the University of Manchester, Aston University and Lancaster University. The University of Manchester promoted the results via our faculty communications and via the NIHR Manchester Biomedical Research Centre.

Methodology

Figure 1 summarises the methodology followed over the course of the project. The full protocol and engagement summary are available via the JLA website: <https://www.jla.nihr.ac.uk/priority-setting-partnerships/childhood-deafness-and-hearing-loss>.

In summary we followed the standard JLA process of:

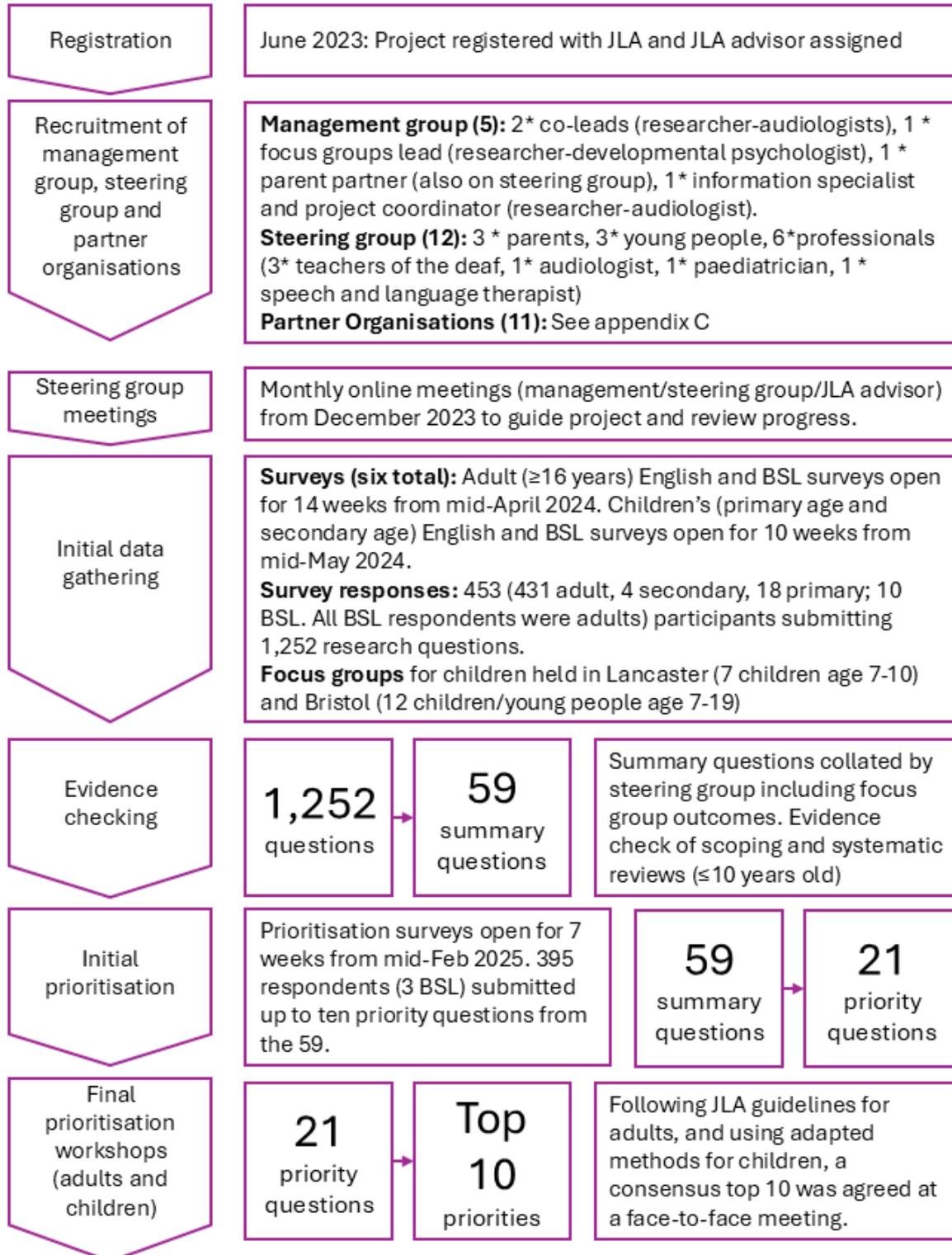
1. Online survey 1: Respondents gave free text responses to the question: **“What should research focus on? Please tell us what questions you think are important in any area related to Childhood Deafness and Hearing Loss.”**
2. Submitted research questions were reviewed, collated into (59) summary questions, and checked against existing evidence
3. Online survey 2: Respondents reviewed the 59 summary questions. In the first part they chose all of the questions which they thought were important **“...please select the questions that you think are priorities for future research on the topic of Childhood Deafness and Hearing Loss. You may select as many questions as you like in this part”**. In the second part they reviewed their personal shortlist and selected up to ten that they thought were most important **“Based on your selections, you will now see a shortlist of the questions from the previous part. Please choose up to maximum of 10 questions you think are the most important. It is fine if you choose fewer than 10 — select only those that you feel are the most important questions”**.
4. Results from online survey 2 were used to rank the 59 questions and get a shortlist of questions, ensuring equal representation from professional and non-professional contributors, and ensuring representation from children. The top ranked questions from both professional and non-professional groups went forward to the shortlist, and this was cross-checked against the themes that emerged from the children’s focus groups.
5. The resulting shortlist of (21) questions was taken to the final prioritisation workshop and the standard JLA process was used, with JLA advisers facilitating the day, to come to a consensus Top 10.

Elements of our work that went beyond the basic JLA requirements outlined above included:

1. Focus groups for children were run during the ‘online survey 1’ data collection phase to ensure children’s voices were heard
2. A total of six versions of survey 1 were available: One each for adults, younger (primary) children, and older (secondary) children, with each of these being available in BSL and English.
3. Two versions of survey 2 were available (BSL and English).
4. A final prioritisation workshop for children was held using specially adapted methods leading to the children’s Top 10.

All decision-making was overseen by the steering group.

Figure 1: Methodology and response statistics



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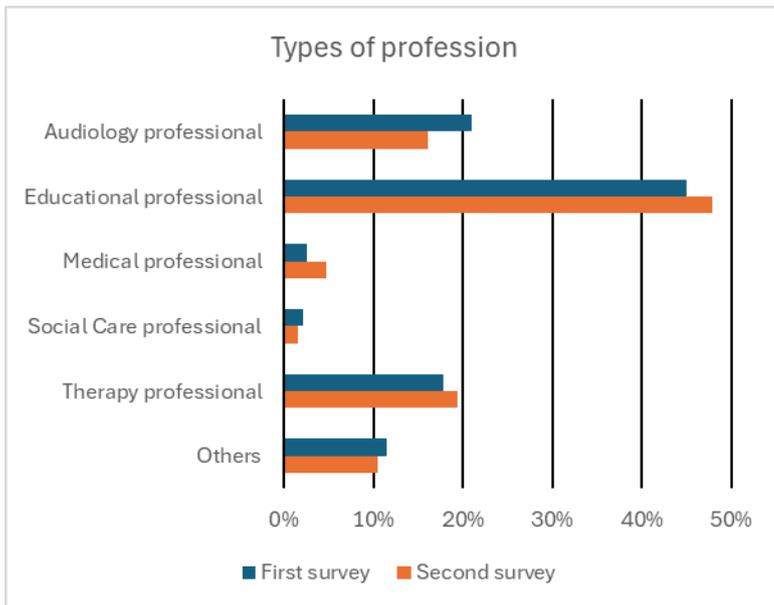
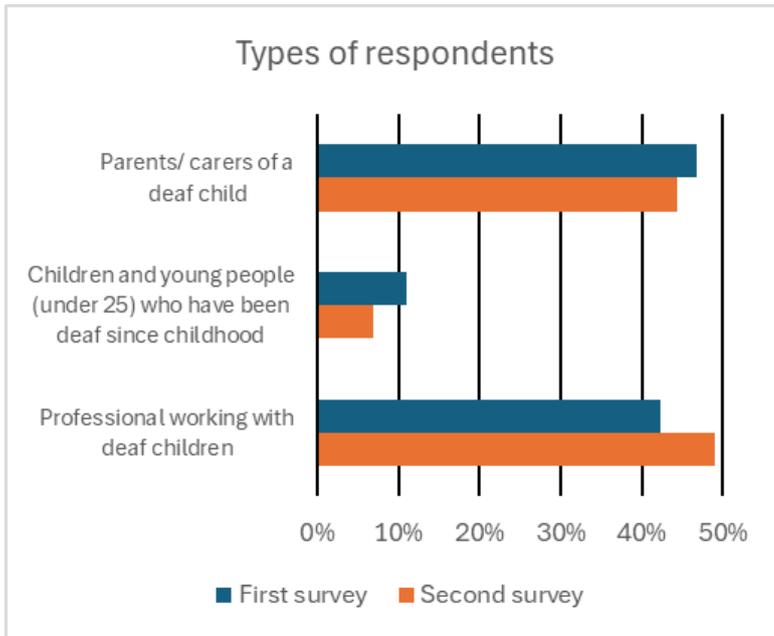
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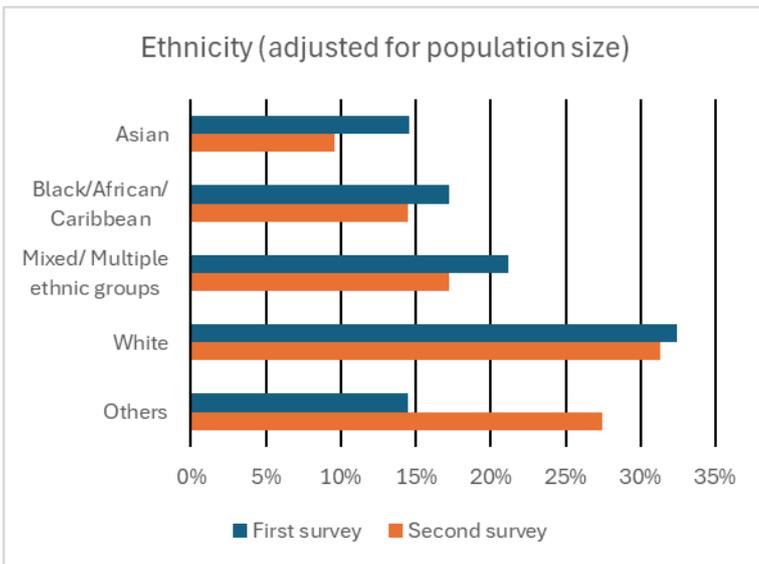
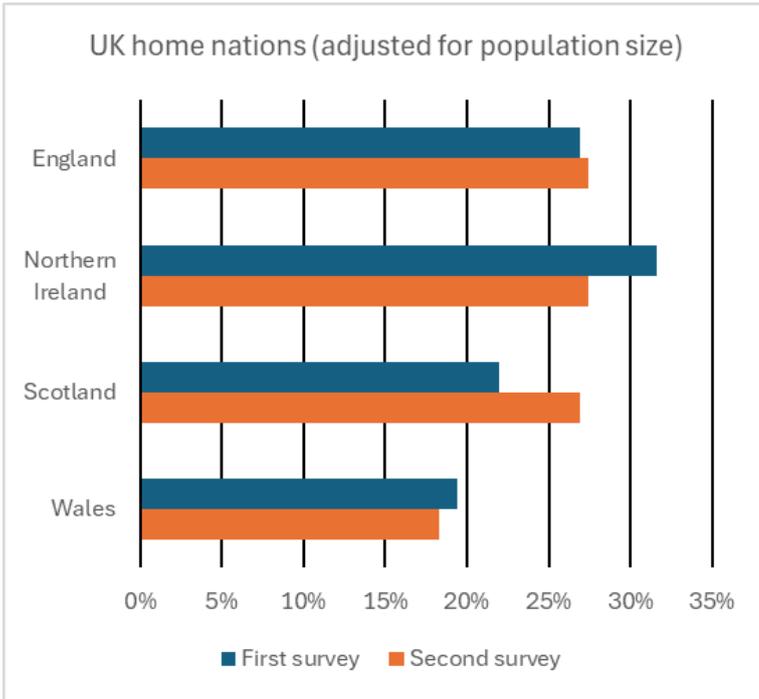
Appendix A: Additional research priorities

Table 3: Rankings of the remaining 11 questions from the adult workshop

#	Priority
11	Early development: How can early development of deaf children be supported, and how does early family intervention, type of play, and workforce training affect outcomes?
12	Cognition: How does childhood deafness affect cognitive functioning and development (such as attention, listening effort, theory of mind, and recognising body sensations) and how can we measure and support this?
13	Incidental hearing and learning: What are the impacts of incidental learning and incidental hearing on deaf children's social, emotional and educational outcomes, including through play?
14	Neurodiversity: What is the relationship between childhood deafness and neurodiversity (e.g. autism, Attention-Deficit/Hyperactivity Disorder (A D H D)), and how can we best support children with these combined conditions?
15	Mental health: How does deafness affect mental health, and what support is most helpful?
16	Transition points: What are the best ways to support deaf children at key transition points throughout their education and into the workplace?
17	Activities: What activities, like sports and music, best support deaf children's development, and how can hearing devices be improved to enable enjoyment of such activities?
18	Schools responding to needs: How can the school system ensure that the voices of deaf children and their families are heard and acted upon in both mainstream and deaf schools?
19	Type of school: What are the measurable outcomes of deaf children educated in different school environments (e.g. schools with or without deaf specialist provision or deaf schools)?
20	Friendships: How does deafness affect friendships and how can deaf children be supported to form positive relationships?
21	Speech and language therapy: How do deaf children benefit from speech and language therapy, and is specialist speech and language therapy better?

Appendix B: Demographic information of survey participants





Appendix C: List of partner organisations

Partner organisations are organisations that represent the interests of deaf children, carers, or clinicians that agreed to support our PSP, primarily by spreading the message of the PSP. This includes sharing surveys and other participation opportunities and helping to disseminate the JLA outputs. Our partner organisations are listed below.

- British Academy of Audiology (BAA)
- British Association of Audiovestibular Physicians (BAAP)
- British Association of Educational Audiologists (BAEA)
- British Association of Teachers of Deaf Children and Young People (BATOD)
- British Society of Audiology (BSA)
- Chloe's and Sophie's Special Ears Fund (CSSEF)
- Ewing Foundation
- Hear Together
- National Deaf Children's Society (NDCS)
- National Sensory Impairment Partnership (NatSIP)
- Royal College of Speech & Language Therapists (RCSLT)