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Priority Setting Partnerships in Audiology: spanning the lifespan of lived experience

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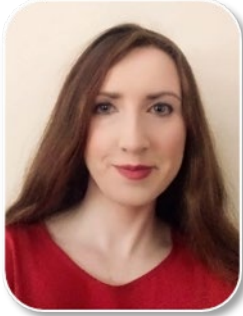
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Headline

Have your say in setting the research agenda for key topics, dementia and hearing loss and childhood deafness.

'Take-home' message

Giving people a voice to shape research priorities for meaningful health advancements

'Hot quote'

"The information we receive from people living with these conditions can only help in the future with research and other initiatives"

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Overview of a James Lind Alliance (JLA) Priority Setting Partnership (PSP)



What is a JLA PSP and why is it important?

The James Lind Alliance (JLA) is a non-profit initiative established in 2004 that brings together patients, carers, and clinicians within JLA Priority Setting Partnerships (PSPs). These partnerships identify and prioritise areas of research uncertainty in a specific health-related topic area. PSPs aim to bridge the gap between what researchers want to research, and what patients, caregivers, and healthcare professionals want to know. 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.

The outcomes of these partnerships are far-reaching and include prompting new research that may lead to a new treatment or service, influencing changes in health service policy and practice, the development of new partnerships and collaborations, identification of new priority areas, changes in research culture, an enhanced focus on patient and public involvement, and the advancement in both personal and professional development (Staley et al., 2019).

What is the JLA PSP process?

A PSP is achieved through a process of consultation and consensus building, which involves several key stages, as illustrated in Figure 1.



Figure 1

Co-existing Dementia and Hearing Conditions PSP

Research has shown a link between dementia and hearing loss, with untreated hearing loss in mid-life being a potentially significant modifiable risk factor for the development of dementia (Livingston et al., 2020). Many people who live with dementia can also have hearing loss. Having both conditions can impact their diagnosis and management and can substantially affect the quality of life of people living with these conditions and their families (Ray et al., 2019). People living with dementia can also experience other hearing conditions, including tinnitus, hyperacusis, and balance disorders.

There are many unanswered questions about co-existing dementia and hearing conditions. For example, *‘What is the best way to assess hearing loss in people living with dementia?’* Given policymakers require patient-focused evidence to guide decision-making, we must enable those who would benefit from research to voice what matters to them. Therefore, a James Lind Alliance (JLA) Priority Setting Partnership (PSP) was launched on World Hearing Day in March 2023, with the aim of partnering with patients, carers and clinicians to identify priorities for research about co-existing dementia and hearing conditions. There will be a particular focus on priorities for research about risk reduction, diagnosis, and treatment.

This PSP is the first of its kind to bring together two health areas and is being carried out by the NIHR Nottingham Biomedical Research Centre and the University of Nottingham in partnership with the JLA, Alzheimer’s Research UK and RNID (the Royal National Institute for Deaf people).

Dr Devina Maru, a GP with specialist interest in ENT, talks about why this PSP is important:

“Research questions about the relationship between hearing loss and dementia can help advance our understanding of how these two conditions are interconnected and lead to improved interventions that enhance the well-being of affected individuals.”

The PSP is led by a diverse steering group, which includes people living with dementia and/or hearing conditions, supporters (e.g., relatives, carers), clinicians (e.g., audiologists, psychiatrists) and representatives of user organisations (i.e., Alzheimer’s Research UK, RNID and the Alzheimer’s Society).

Sue Strachan, a champion for ARUK living with dementia, and a member of the steering group, talks about the potential long-term outcomes of the PSP:

“The information we receive from people living with these conditions can only help in the future with research and other initiatives.”

This partnership is keen to learn the views of people living with dementia and/or hearing conditions, their supporters, health and social care professionals, people who are part of the Deaf community and the general public who have an interest in this topic.



The image is from the Centre for Ageing Better.

An initial survey has gathered people's top questions about risk reduction, diagnosis and treatment related to co-existing dementia and hearing conditions. The questions from the initial survey were grouped and checked against existing evidence to identify if questions had already been answered by research. The refined list of questions has been taken forward to a second survey to be ranked in order of importance. A top 10 will then be decided via workshop(s).

If you or someone you know might like to take part or you want to find out more, you can visit the <https://www.jla.nihr.ac.uk/priority-setting-partnerships/coexisting-dementia-and-hearing-conditions/> or use the QR code.



You can also follow us on Twitter/X [@DementiaHearPSP](https://twitter.com/DementiaHearPSP), or email the PSP Co-ordinator Dr Sian Calvert , at sian.calvert@nottingham.ac.uk.

Childhood deafness and hearing loss PSP

We now have a wealth of evidence showing the importance of quality, early intervention for children with hearing loss, to ensure they have the same opportunities as their peers. This also applies to children with mild and unilateral hearing losses. Despite access to early intervention, there is still an attainment gap between children with hearing loss and their normally-hearing peers. It is of vital importance to understand why this is, to determine the support needed for children with hearing loss, and how to provide it.

The Childhood Deafness and Hearing Loss Priority Setting Partnership 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. We are delighted to be working with a wide range of Partner Organisations, including the British Society of Audiology, British Academy of Audiology, British Association of Teachers of Deaf Children and Young People, National

Sensory Impairment Partnership, British Association of Educational Audiologists, Hear Together, and the Ewing Foundation. And we are finding new partner organisations to work alongside all of the time.

In addition to our committed steering group, we have formed expert reference groups of people with lived experience: young people with hearing loss, families of children with hearing loss, and professionals working with children with hearing loss. Our groups ensure a diverse representation from across the UK. These links between researchers, health professionals, patients, and carers are fundamental to the success and the longevity of the JLA process. This ensures, not only that we establish a meaningful 'Top 10' research priorities that are important to those with lived experience, but that we also work hard to make sure those questions are addressed by researchers, and that the results are acted on by health and education professionals. Involving children and young people in the process is particularly important and rewarding. We aspire to maintain ongoing connections with our Young People's Advisory Group as we move forward into the future.

Our parent partner, Juliet Viney, has worked with us on the project from the start, and sits on the steering group as a parent of a child with profound hearing loss. Juliet is a great advocate for the Priority Setting Partnership: "This is such an exciting opportunity for deaf children, young people and their parents to be able to shape their own 'Top 10' research questions that really matter to them and help all deaf children achieve their full potential."



Parent Partner Juliet Viney with her Daughter Bess

Our Priority Setting Partnership is currently in phase 2: Collecting initial priority questions via a survey. Please take a few minutes to complete the survey to tell us what you think the research priorities in childhood deafness are. Equally important, please share this opportunity to children, young people and families affected by childhood deafness.

In addition to the questionnaires we are also running focus groups, led by the team at Lancaster University with expert facilitators to encourage children with hearing loss and their families to be able to express themselves fully and share what is important to them. If you would like more information, or to get involved, please get in touch using the contact details below.

Access the survey: <https://www.ndcs.org.uk/research-priorities>

You can also get in touch with the Priority Setting Partnership team at: childhooddeafness@manchester.ac.uk. We would love to hear from you.



References

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