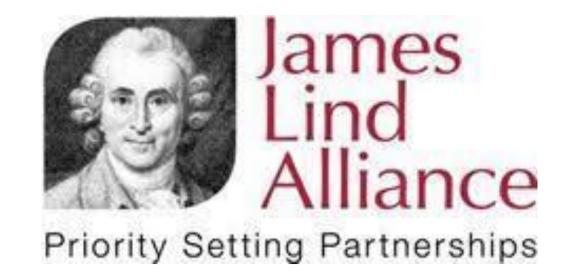
NILLR Nottingham Biomedical Research Centre





Generating priorities for future dementia and hearing research: **A James Lind Alliance Priority Setting Partnership**

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2. Method

Hearing loss is one of the largest potentially modifiable risk factors in midlife for the development of dementia¹. Dementia and hearing conditions are common in older adults and often coexist, which can impede their assessment and management, and impact quality of life².



People who live with these conditions, along with caregivers, are often under-represented in research and may belong to additional underserved groups (e.g., ethnic minority groups, LGBTQ+ community)^{3,4}. For health research findings to apply to everyone, we need to ensure these underserved groups have the opportunity and are supported to contribute.



There are many unanswered about co-existing dementia and hearing conditions. Since policymakers require patient-focused evidence, we must enable those who would benefit from research to voice what matters to them.

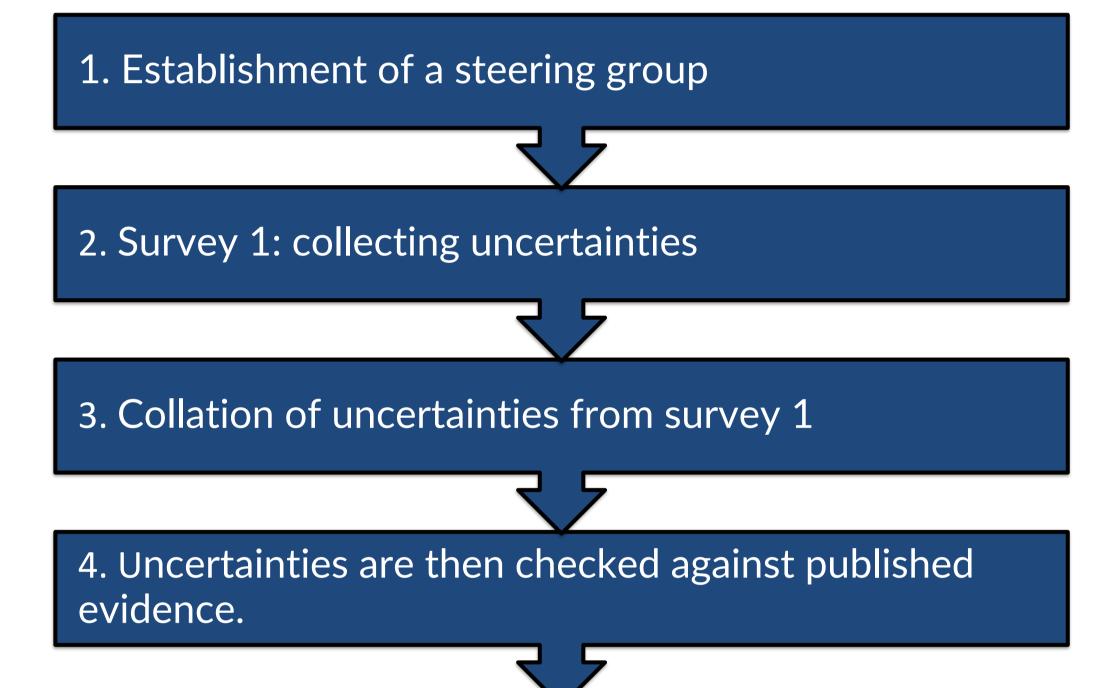
A James Lind Alliance (JLA) Priority Setting Partnership (PSP) has been launched to prioritise unanswered research questions about coexisting dementia and hearing conditions (e.g., hearing loss, tinnitus, hyperacusis).

Objectives

Scope – To prioritise research uncertainties about the prevention, diagnosis, and treatment of co-existing dementia and hearing conditions.

Participants – People living with dementia and/or hearing conditions; family, loved ones, and carers of those living with dementia and/or hearing conditions; professionals from healthcare and social care; user organisations (e.g., charities) and the general public.

Stages - The PSP involves consultation and consensus building through several key stages⁵:



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1) To work with patients, carers and clinicians to identify uncertainties about the risk reduction, diagnosis, and treatment of coexisting dementia and hearing conditions.

2) To agree the top 10 research uncertainties by consensus.

3) To disseminate results to guide future research and policy.

5. Survey 2: Interim priority setting

6. A final priority setting workshop to agree the top 10 uncertainties.

Throughout the PSP, evidence-based strategies for inclusivity will be incorporated^{3,4}.

3. Results

Stage 1 – Establishment of a steering group

The PSP is led by a diverse steering group that includes:

4 People with lived experience of dementia/hearing conditions

1 Hyperacusis expert



1 Person who supports/cares for a person living with dementia and hearing loss

7 Clinicians (e.g., Audiologist, GP, **Psychiatrist**)

3 User Organisation Representatives (i.e., RNID, **Alzheimer's Research UK, Alzheimer's Society**)

Stage 2 – Survey 1: Collecting initial priorities

Why not complete the initial survey to help shape future research about coexisting dementia and hearing conditions?



4. Conclusion and Next Steps

This project will produce a strategic agenda to direct future studies, funding, and policy in the field of dementia and hearing conditions.

This agenda will help to ensure that future studies address research questions that are important to those who will be directly impacted by its outcomes.

5. References

- 1. Livingston et al. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, 396, 413 – 446.
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- 3. National Institute for Health and Care Research (2022), "NIHR Equality, Diversity & Inclusion Strategy 2022-2027".
- 4. National Institute for Health Research. (2022). Improving inclusion of under-served groups in clinical research: Guidance from INCLUDE project v2.0.
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