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

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1. Introduction

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

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**

1. To work with patients, carers and clinicians to identify uncertainties about the risk reduction, diagnosis, and treatment of co-existing dementia and hearing conditions.
2. To agree the top 10 research uncertainties by consensus.
3. To disseminate results to guide future research and policy.

2. Method

**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 stages:

1. Establishment of a steering group
2. Survey 1: collecting uncertainties
3. Collation of uncertainties from survey 1
4. Uncertainties are then checked against published evidence.
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**
- **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


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