

Shaping future research about co-existing dementia and hearing conditions: Adapting the James Lind Alliance Priority Setting Partnership process to support inclusivity.

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1. Introduction

- The James Lind Alliance Priority Setting Partnership (PSP) engages with people with lived experiences, caregivers, and healthcare professionals to identify research priorities through consultation and consensus building.
- PSPs place individuals on an equal footing, but it is important to ensure that everyone has the opportunity and is supported to contribute.
- The JLA PSP in co-existing dementia and hearing conditions is the first of its kind to bring together two health conditions; both of which are accompanied by communication difficulties.

Objective:

To support accessibility and inclusion of people with lived experience of dementia and hearing conditions and groups typically underserved by research in the PSP process



2. JLA Process

- Survey 1:** Collect questions about dementia & hearing conditions.
- Analysis:** Group the questions to create summary research questions.
- Evidence Checking:** Remove or revise questions that have been answered or partially answered by past research.
- Survey 2:** Rank the questions in order of priority.
- Workshop:** Agree the top 10 most important questions.

For more information about the PSP partnership and final workshop please see the WCA presentation on 21st September in the Age-Related Loss and Cognition session or scan the QR code.



3. Adaptations

Strategies to promote inclusivity and accessibility were interwoven throughout the traditional JLA PSP process.



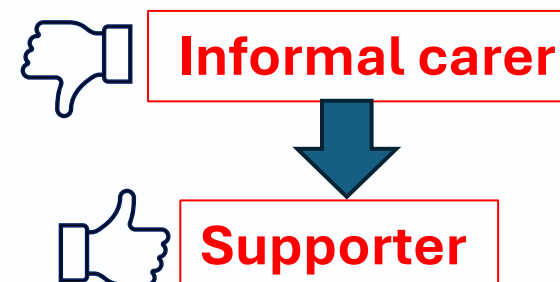
Held all steering group meetings online to support preferred communication style.



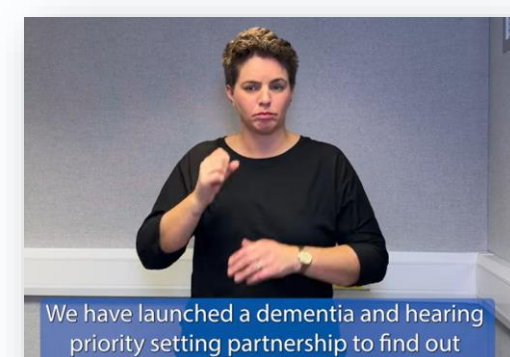
Produced both summary and full versions of documents, e.g. meeting notes and communication materials.



Produced and shared materials in a range of ways (e.g. Surveys in large print sent via post)



In partnership with the Steering group decided on key terms to use throughout the PSP



Had surveys and promotional materials translated into British Sign Language (BSL).

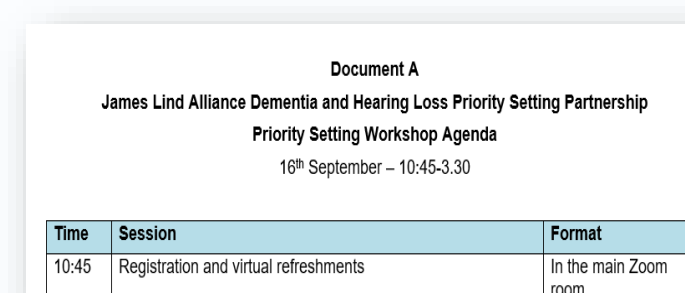
This PSP was the first to produce BLS versions of the surveys.



Co-produced animations with people with lived experience to share information about the PSP.



Recruited participants via various channels to try and reach a range of people, e.g., posters in waiting rooms, social media posts and user organisation blogs.



Adapted the workshop process in collaboration with the JLA to support inclusion, e.g. shorter sessions

3. Outcomes

Who did we reach?	Survey 1 (N=404)	Survey 2 (N= 560)
Health and Social Care professionals	169	175
Under-served groups		
Older adults - 80 years and above	33	65
Non-Binary	3	1
Living with dementia/MCI	32	51
Living with hearing conditions	296	459
Supporter of someone living with dementia	186	257
Supporter of someone living with hearing	221	324
conditions		
Disability or health condition	112	204
Mental health condition	43	62
Lives in a rural/remote area	49	75
LGBTQ+ community	17	20
Unrecognised or no qualification	4	11
Low income	32	63
Unhoused/homeless	4	3
Minority or marginalised group	14	7
Ethnic group		
White	353	529
Asian	19	13
Mixed/Multiple groups	12	3
Black/African/Caribbean	27	3
Other	8	6

4. Summary and Next steps

- The adaptations made led to the inclusion of a wide and diverse group of individuals, meaning future research agendas will be influenced by those it will most impact.
- Implementing various strategies throughout the process to encourage diverse participation is crucial, as no one size fits all.
- The adaptations tailored to accommodate a range of people within the JLA process could serve as a guide for future PSPs.

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