**Top 10 hyperacusis research priorities in the UK**

Hyperacusis involves a reduced tolerance or increased sensitivity to everyday sounds, whereby they become intense and overwhelming. It is experienced by 3.7% of children and up to 9.2% of adults, with a higher prevalence is certain populations such as those who have Williams’ syndrome or autism [1]. Hyperacusis-associated problems are many, including fear, pain, avoidance behaviours, and impairments to quality of life such as reduced ability to work [3]. For children with hyperacusis, the classroom can be particularly challenging, and strategies are needed to ensure their wellbeing and educational needs are met. Tyler [2] proposed a framework for categorising hyperacusis according to features of the experience, suggesting loudness, annoyance, fear, and pain are important defining characteristics. For many, hyperacusis is also isolating, with thousands turning to Facebook and other social media for information and support. Clinical assessment of hyperacusis includes sound-based tolerance tests and questionnaires to measure the impact it has on an individual’s life [4]. Treatment approaches include sound and cognitive behaviour therapies, though no formal clinical practice guidance currently exists [5].

The Hyperacusis Priority Setting Partnership (PSP) was formed to identify the questions about hyperacusis most important to healthcare professionals and people with lived experience of hyperacusis (patients and parents). The PSP included people with lived experience of hyperacusis, healthcare professionals (clinical/cognitive psychology, audiology, otolaryngology), researchers, and representatives from organisations involved in supporting people with hyperacusis, funding research, and communicating science.

Using James Lind Alliance methods, priority setting started with two surveys. In the first, 312 respondents worldwide submitted 2370 research questions (termed “uncertainties”). Of these respondents, 179 were people with lived experience, and 86 were healthcare professionals, of whom one also had hyperacusis. Thirty-eight respondents were either parents, carers, family members, friends, or teachers. Submitted questions were verified as unanswered in the research literature. Questions were synthesised and 85 were listed in a second survey. In the second survey, 327 participants voted for their individual priorities. From the 28 receiving the most representative vote, 10 research priorities were agreed during a final workshop involving 21 participants, held in Nottingham, UK, in July 2018 (panel). The ‘Top 10’ research priorities for hyperacusis focus on treatment, cause, mechanism, prevalence, and healthcare provider knowledge and training. These priorities provide an important platform for researchers, funding bodies, and the healthcare sector to ensure future research focuses on questions that are important to healthcare practitioners and people with lived experience of hyperacusis.

We declare no competing interests. This work was supported by funding provided by the British Society of Audiology and Action on Hearing Loss. KF and DJH are funded by the National Institute for Health Research (NIHR) Biomedical Research Centre programme, however the views expressed as those of the authors and not necessarily those of the NIHR, the NHS or the Department of Health and Social Care.

**Kathryn Fackrell, Linda Stratmann, Toto Anne Gronlund, Derek J Hoare, on behalf of the Hyperacusis Priority Setting Partnership Steering Group (appendix)**

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| *Panel:* Top 10 research priorities for hyperacusis   1. What is the most effective treatment approach for hyperacusis in children? 2. What is the prevalence of hyperacusis in a general population and other specific populations (e.g. people with autism, mental health issues, learning disabilities, hearing loss)? 3. Are there different meaningful types of hyperacusis? 4. What is the essential knowledge/training required for health professionals to appropriately refer or effectively manage hyperacusis? 5. Which treatment approaches are most effective for different types or severities of hyperacusis? 6. Is hyperacusis due to physical or psychological issues or is it a combination of both? 7. Which psychological therapy (e.g. counselling, Cognitive Behavioural Therapy, mindfulness) is most effective for hyperacusis? 8. What management approach for hyperacusis is most effective for adults/children with autism? 9. What is the best way of using sound in therapy for hyperacusis? 10. Which self-help interventions are effective for hyperacusis? |

**Supplementary appendix**

***The Hyperacusis Priority Setting Partnership Steering Group***

**Patient representatives:**

Linda Stratmann, User organisation, founder and co-moderator of Facebook group Hyperacusis Support & Research, and person with lived experience.

Tracey Pollard, Action on Hearing Loss, patient representative.

Carolyn Farrell, person with lived experience.

Mike Meadows, person with lived experience.

Nic Wray, person with lived experience.

Sarah Chapman, Cochrane UK Knowledge Broker.

Hilary Hodgson, Parent.

**Clinical representatives:**

Carol MacDonald, CBT psychotherapist and Clinical Psychology Lecturer.

David Baguley, Clinical Scientist (audiology).

Jacqueline Sheldrake, Audiologist.

John Phillips, ENT surgeon.

Josephine Marriage, Paediatric audiologist.

Peter Byrom, Audiologist.

Rosie Kentish, Clinical Psychologist.

Veronica Kennedy, Audiovestibular Physician.

**Additional (non‐voting) steering group members:**

Derek Hoare, Researcher, Nottingham.

Kathryn Fackrell, Researcher, Nottingham.

Helen Henshaw, Researcher, Nottingham.

**The literature search was performed by:**

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**The partnership and priority setting process were supported and guided by:**

Toto Anne Gronlund, PSP Chair, The James Lind Alliance (JLA).

Sheela Upadhyaya, The James Lind Alliance (JLA).

Katherine Cowan, The James Lind Alliance (JLA).