

Identifying and Prioritising Unanswered Research Questions for People with Hyperacusis: James Lind Alliance Hyperacusis Priority Setting Partnership

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For which topic were research priorities identified?

hyperacusis

In which location was the research priority setting conducted?

international

Why was it conducted at all?

Hyperacusis remains medically unexplained with no definitive diagnosis, aetiology or cure. Despite its prevalence and clinical implications, hyperacusis research is in its infancy and there are many controversies in the field. With such an open field, it is essential to identify and address research priorities that are immediately relevant and important to those affected by hyperacusis, and those who provide care for them.

What was the objective?

to identify the questions about hyperacusis that are important to people with lived experience, parents/carers, family, educational professionals and healthcare practitioners involved in the care of people who have hyperacusis and to prioritize these questions according to the relevance and importance to these groups to direct future research and funding in hyperacusis

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

Setting up PSP: August 2017. Survey: October 2017 - January 2018. Interim ranking: May 2018 - July 2018. Workshop: July 2018

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: forming steering group, defining scope. Step 2: identifying uncertainties: survey coproduced with steering group, participants were asked: "What question(s) about the how hyperacusis is assessed and/or diagnosed would you like to see answered by research?", 2370 submissions. Step 3: data processing: refining uncertainties and identifying existing evidence: categorizing and refining uncertainties, verifying them as uncertainties and creating list of indicative questions, review by steering group, resulting in 85 indicative questions. Step 4: interim ranking: via survey, participants were asked to select top 10 questions, all indicative questions that were moved to the top 10 box were ranked based on the number of summed responses for each stakeholder group using weighing, results reviewed, 28 indicative questions taken forward to workshop. Step 5: final prioritization: workshop: small group discussions, participants were asked to rank questions, group rankings combined, new small groups formed and again ranking, plenary session to find consensus on top 10

Which stakeholders took part?

People with lived experience of hyperacusis, parents/carers, family and friends, educational professionals and healthcare professionals who support and/or treat adults and children who experience hyperacusis, including but not limited to surgeons, audiologists, psychologists and hearing therapists. Survey: 312 participants: people with lived experience (58%), healthcare professionals from a range of disciplines (28%), parents/carers (7%) and family and friends (1%) of those with hyperacusis. Interim ranking: 327 participants: people with lived experience (67%), healthcare professionals (25%) and then a small number of parents/carers (6%), family and friends (1%), and educational professionals (1%). Workshop: 21 participants, representing people with lived experience of hyperacusis (n=6) (including two teachers), parents of children living with hyperacusis (n=5) and healthcare professionals (n=10) from a range of disciplines that care for and support those with hyperacusis (including audiologists, a paediatric clinical psychologist, clinical psychologists and an audiological physician).

How were stakeholders recruited?

The survey was circulated via steering group members (including to the hyperacusis research.net international network based in the USA), partner organization contact lists, promotion in newsletters and national conferences, printed posters in clinics and through dedicated social media channels (including to the international membership of the Hyperacusis Support and Research Facebook group which is led by the UK and US administrators). Workshops, plenary sessions and educational professionals, people with lived experience of hyperacusis and parents of children living with hyperacusis were invited to participate via contact details submitted following the two surveys, organization contact lists and social media. Participants were selected with the aim of 50:50 representation for 'lived experience' (including adults, children and parents) and professionals.