

Nottingham  
Biomedical Research Centre

  
*National Institute for  
Health Research*

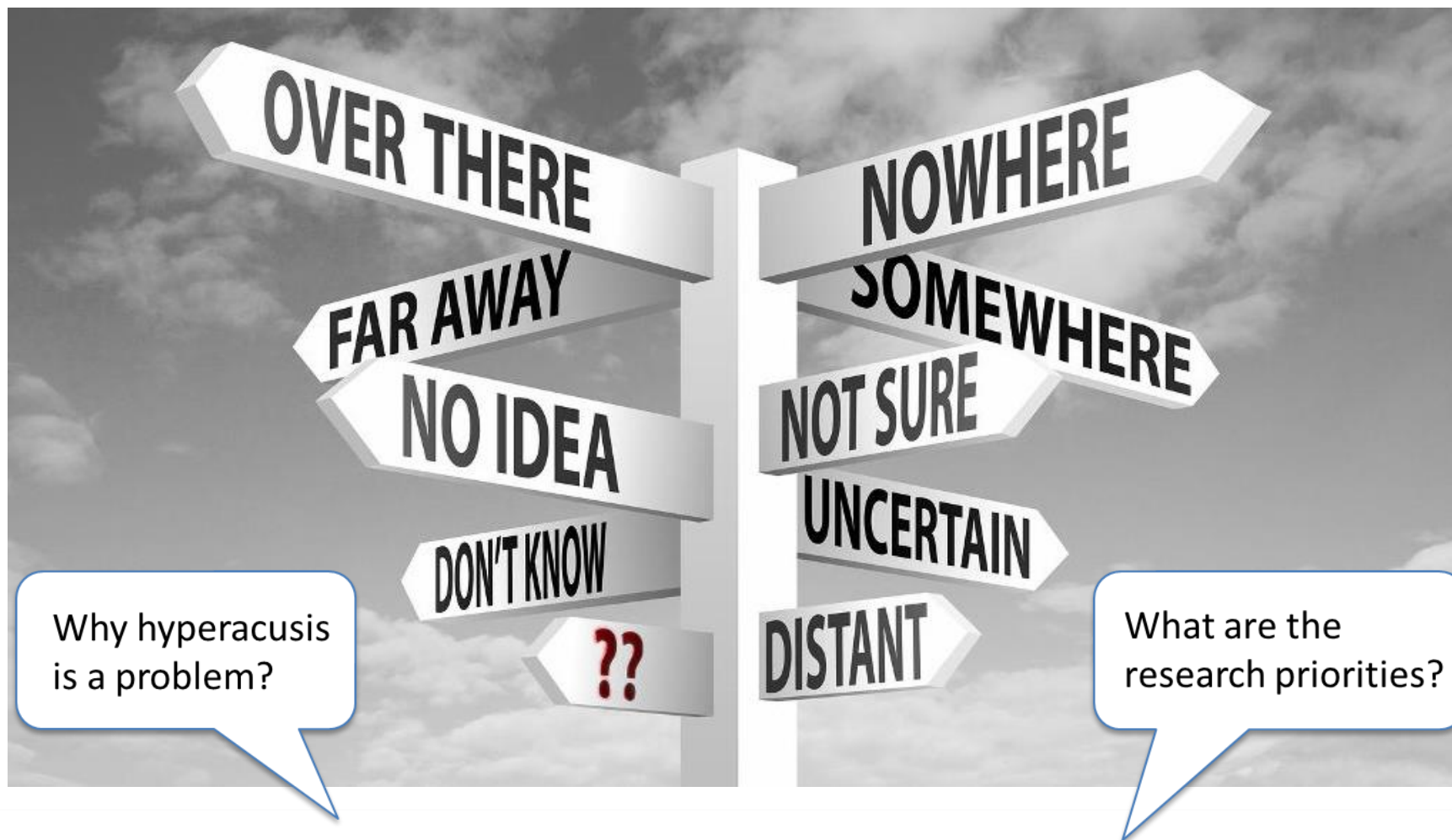
# Prioritising hyperacusis: The Top 10 research priorities

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NIHR Evaluation, Trials and Study Coordinating Centre, University of  
Southampton

*Pushing the frontiers of medical science*



## “Why is Hyperacusis a Problem?”

- **357 participants** (54% male, M: 46.5yrs) reported **26 hyperacusis-related problem domains**
- **Quality of life, Fear and Avoidance** were most commonly reported.
- **Consequences for tinnitus** only reported in the clinical population
- **Losing independence**, only reported in the research population.

Domain of hyperacusis	Rank: n codes	Sample of codes allocated to domains	Clinic	Research
Quality of life	1 <sup>st</sup> : 106	cannot live my life; impact on everything	✓	✓
Fear	2 <sup>nd</sup> : 72	fearful of making it worse; scared for future	✓	✓
Avoidance	3 <sup>rd</sup> : 54	having to avoid situations (which becomes like jigsaw puzzle)	✓	✓
Pain	4 <sup>th</sup> : 51	Hurts; painful; dishes banging and silverware feels like needles in my ear	✓	✓
Activity Limitations	5 <sup>th</sup> : 45	influences what I do socially; stops social life almost completely	✓	✓
Impact on relationship with family and friends	6 <sup>th</sup> : 43	stops me from enjoying my children; Some friendships did not endure the stress of what sound sensitivity does to me	✓	✓
Annoyance	7 <sup>th</sup> : 41	annoys me; it bothers my ears	✓	✓
Safety behaviour	8 <sup>th</sup> : 39	Starting to think about where I go because of it; Cannot do normal, everyday things without ear protection.	✓	✓
Work limitations	9 <sup>th</sup> : 38	I am now applying for SSDI (disability insurance) because I can no longer work full-time.	✓	✓
Emotional reaction	10 <sup>th</sup> : 29	getting me down; distresses me; it makes me so angry	✓	✓
People not understanding	11 <sup>th</sup> : 23	Nobody, even doctors, understands; Some people look at me as if I'm making it up.	✓	✓
Bodily complaints	12 <sup>th</sup> : 22	Exhaustion; Fatigue; headaches	✓	✓
Sense of control	13 <sup>th</sup> : 20	I have no control of it; unable to control the sounds coming at me	✓	✓
Effect on concentration	13 <sup>th</sup> : 20	can't think properly	✓	✓
Coping	14 <sup>th</sup> : 18	not being able to cope (with pain); Trying to deal with or hide symptoms	✓	✓
Communication - listening ability	15 <sup>th</sup> : 17	I can't engage in conversation; Cannot communicate normally	✓	✓
Isolation	16 <sup>th</sup> : 15	Feeling isolated in social setting; Think 'shut in'	✓	✓
Vigilance	17 <sup>th</sup> : 14	it puts me on my guard all the time	✓	✓
Not normal	17 <sup>th</sup> : 14	stops me feeling normal	✓	✓
Consequences for tinnitus	18 <sup>th</sup> : 13	might trigger tinnitus	✓	
Sleep	19 <sup>th</sup> : 10	can't sleep if there are sounds around	✓	✓
Stress	20 <sup>th</sup> : 10	creates tremendous stress	✓	✓
Decreased hearing	21 <sup>st</sup> : 9	cannot hear people in loud situations	✓	✓
Anxiety	21 <sup>st</sup> : 9	anxious about noise exposure	✓	✓
changing perception of sound	22 <sup>nd</sup> : 7	Sounds are not the same.	✓	
Losing independence	23 <sup>rd</sup> : 4	I can no longer go shopping by myself in a mall		✓

## What does this tell us?

- There are numerous problem domains that might affect their hyperacusis patients.
- Current clinical questionnaires may only reflect some of these problem domains
- Fear of damage, fear for the future and fear of the unknown is main problem to overcome.
  - ? Develop Information or support to help with fear
  - ? More accessible information

*Review Article*

## **Clinical Interventions for Hyperacusis in Adults: A Scoping Review to Assess the Current Position and Determine Priorities for Research**

**NHS**

**National Institute for  
Health Research**

Kathryn Fackrell,<sup>1,2</sup> Iskra Potgieter,<sup>1</sup> Giriraj S. Shekhawat,<sup>3,4</sup> David M. Baguley,<sup>1,2</sup>  
Magdalena Sereda,<sup>1,2</sup> and Derek J. Hoare<sup>1,2</sup>

1. How hyperacusis is currently defined in research studies?
2. How is it currently measured?
3. What is the level of evidence for current management options?

- Management strategies were typically evaluated in patients reporting hyperacusis as a secondary complaint or as part of a symptom set.
- **Recommendations for future work indicated all management options need more evidence and larger studies.**



What really matters to people with lived experience of hyperacusis?

What questions do healthcare professionals need to be answered?



**James  
Lind  
Alliance**

Priority Setting Partnerships



- Working together with patients and professionals to identify and prioritise unanswered questions for research to target.
- Project steered by patients and professionals
  - All decisions about project scope, information and dissemination are made by the steering group
  - All information co-produced








Carolyn Farrell  
Rosie Kentish  
Peter Byron






- 
- Initial survey – gathering uncertainties
    - Ask for people with hyperacusis and professionals to submit any questions they have about hyperacusis

- 
- Develop framework for questions
    - Remove out of scope, group and summarise remaining questions
    - Check questions have not already been answered by research

- 
- Interim prioritisation survey
    - long list of unanswered questions reduced the list of questions into top 30

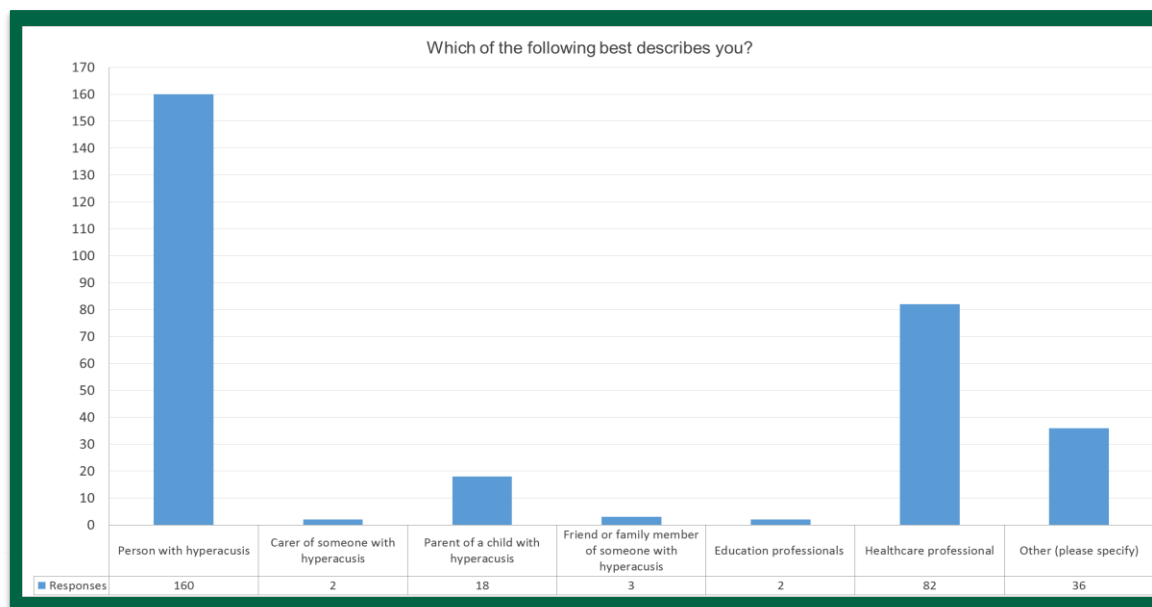
- 
- Prioritisation workshop
    - Discuss and finalise top priorities for research



**TOP 10 RESEARCH PRIORITIES IDENTIFIED**

- Initial survey – gathering uncertainties
  - Ask for people with hyperacusis and professionals to submit any questions they have about hyperacusis

**Broad scope** - Causes, Assessment, Management, Prevention, Support and care, Services



- A total of 312 people submitted over 2500 questions about hyperacusis.

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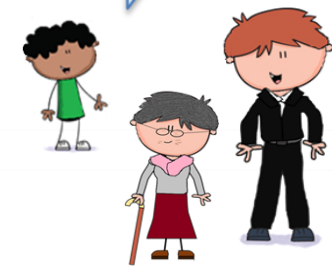
Is hyperacusis  
treatable with CBT?

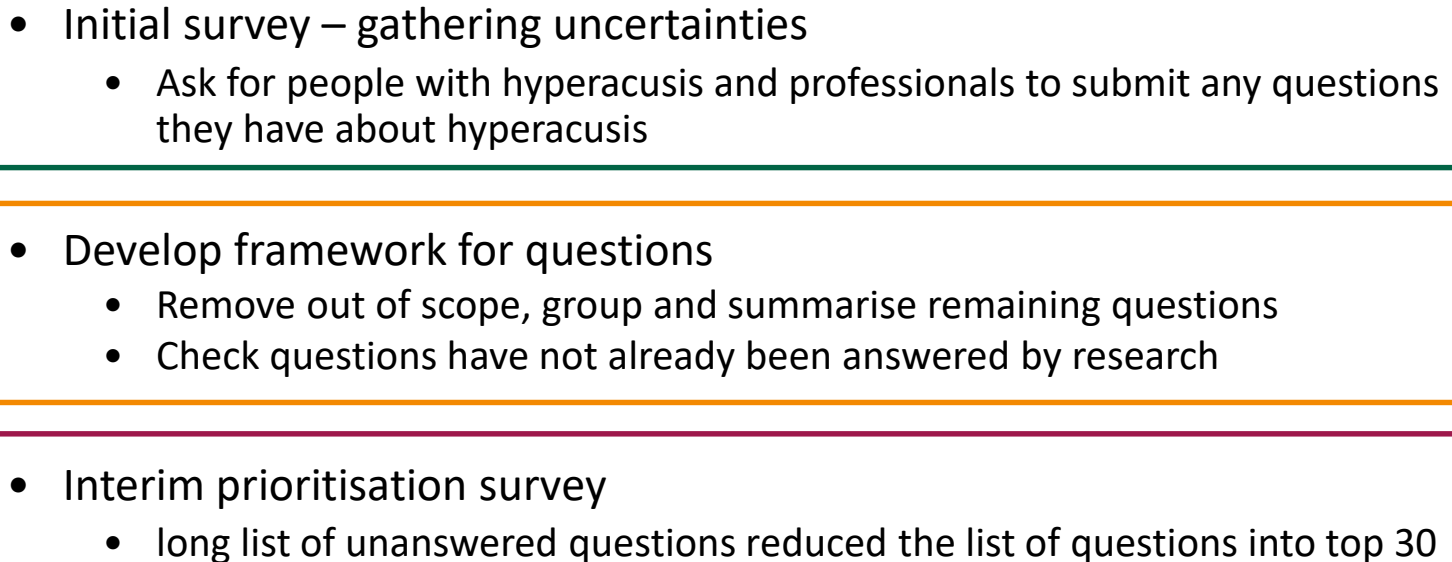
How effective is good online available  
information for preventing families to  
need further healthcare access?

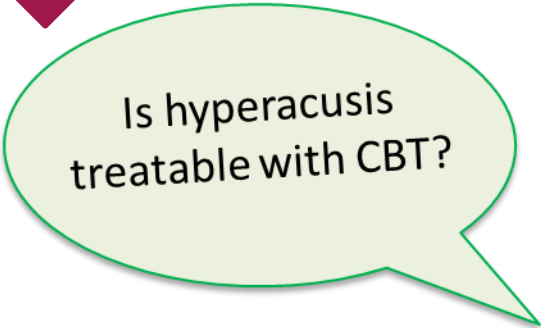
Do GPs know  
how best to  
manage  
hyperacusis?

Can hearing aids actually  
make hyperacusis worse by  
over amplifying?

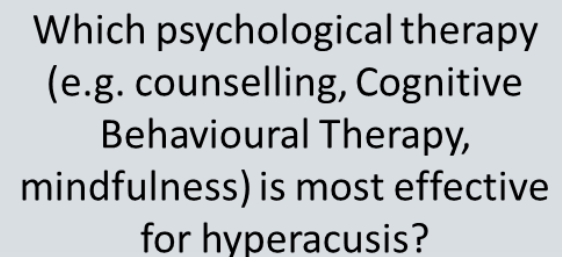
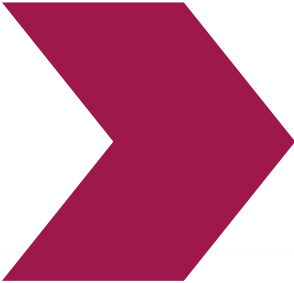
How do you manage  
hyperacusis in children?



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Is hyperacusis  
treatable with CBT?



Which psychological therapy  
(e.g. counselling, Cognitive  
Behavioural Therapy,  
mindfulness) is most effective  
for hyperacusis?

- What assessments should be conducted in the workplace?
- What are the precautions a dentist should use for their patients who have hyperacusis?
- Is private healthcare for hyperacusis more effective than NHS usual care?
- Which treatment approach is most effective for different categories of hyperacusis?
- What hyperacusis self management techniques help with invasive procedures (e.g. having dental work)?
- Which health professionals should be involved in the care of adults with hyperacusis?
- Does diet have an effect on hyperacusis?
- What drugs are effective for hyperacusis?
- What is the best information and guidance for parents dealing with hyperacusis in their children?
- How should hyperacusis be assessed in different populations?
- What hearing aid settings are safest for people with hyperacusis?
- What are the indicators for psychological/specialist care for someone with hyperacusis?
- Which psychological therapy (e.g.

69 of 85 remaining

**Questions of interest**

Are any complementary (relaxation, yoga, meditation, hypnotherapy) or alternative therapies (laser therapy, vibration therapy) effective for hyperacusis?

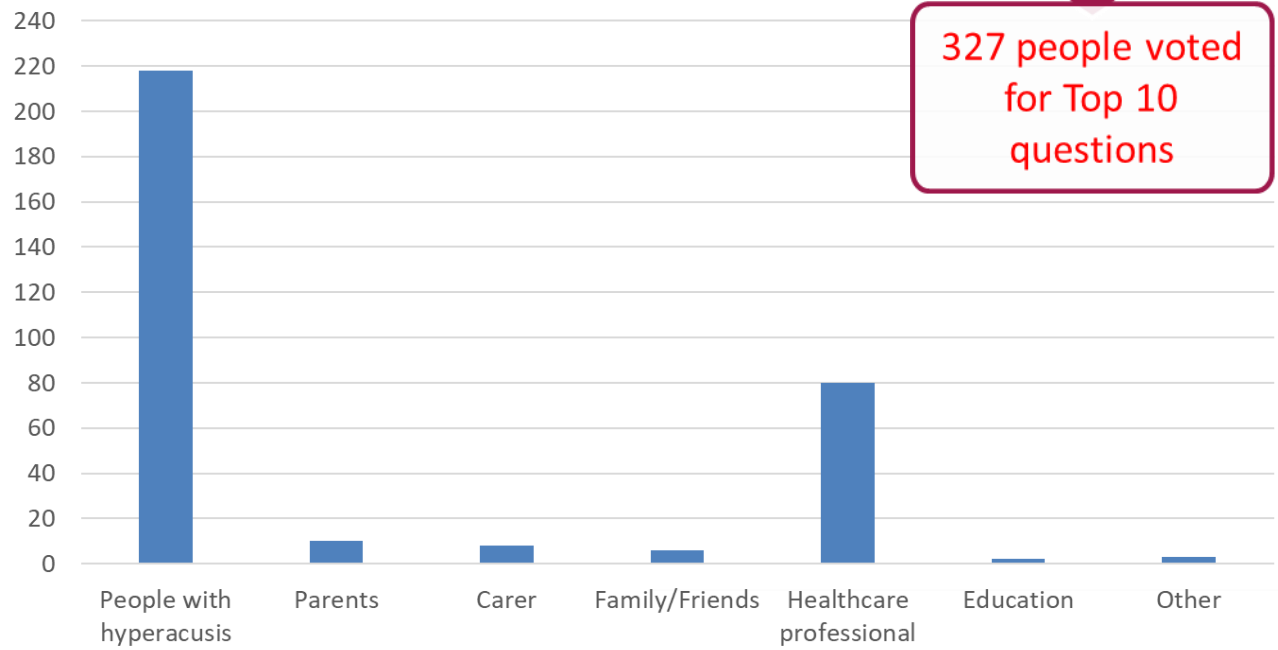
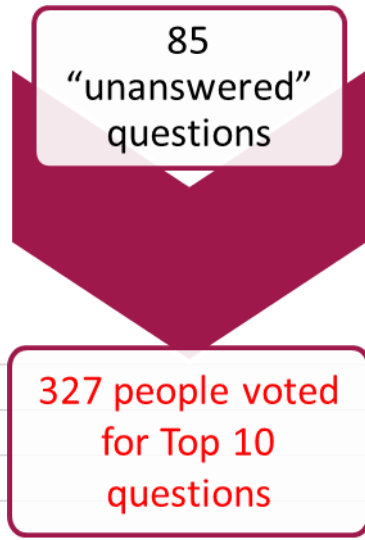
1 item

**Top ten questions**

What hyperacusis self management techniques help with invasive procedures (e.g. having dental work)?


What is the essential knowledge/training of health professionals to be hyperacusis specialists?

1 of 10 items

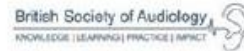


# Top 28 questions

Ref	Question
A	Are there different meaningful types of hyperacusis?
B	Is hyperacusis due to physical or psychological issues or is it a combination of both?
C	Is there an association between hyperacusis and other ear-related conditions (e.g. superior canal dehiscence syndrome, Meniere's, Waardenburg syndrome, vertigo, vestibular migraines)?
D	Which criteria should be met to diagnose hyperacusis in adults/children?
E	Which psychological therapy (e.g. counselling, Cognitive Behavioural Therapy, mindfulness) is most effective for hyperacusis?
F	Which interventions in a school setting are useful for children with hyperacusis?
G	What is the essential knowledge/training required for health professionals to appropriately refer or effectively manage hyperacusis?
H	What area(s) of the brain and patterns of activity is/are associated with hyperacusis?
I	What is the most effective treatment approach for hyperacusis in adults?
J	What is the relationship between mental health and hyperacusis?
K	Which drugs are effective for hyperacusis?
L	Does avoidance of sound improve hyperacusis or make it worse?
M	Can noise exposure cause hyperacusis (or make it worse)?
N	Is hyperacusis related to physical changes in the ear or brain?
O	What are the 'red flags' for serious underlying conditions in hyperacusis?
P	What is the best way to differentiate hyperacusis from other hearing conditions (e.g. recruitment, misophonia, Meniere's, tinnitus)?
Q	What management approach for hyperacusis is most effective for adults/children with autism?
R	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)?
S	Which self-help interventions are effective for hyperacusis?
T	Which treatment approaches are most effective for different types or severities of hyperacusis?
U	Does nerve damage cause the pain associated with hyperacusis?
V	What is the association between hyperacusis and dementia?
W	Would restoring hearing (e.g. regenerating nerve cells) improve hyperacusis?
X	What is the most effective treatment approach for hyperacusis in children?
Y	What is the best way of using sound in therapy for hyperacusis?
Z	What are the risk factors for developing hyperacusis or making it worse?
AA	Is hyperacusis linked to other sensitivities/conditions?
BB	What care is most effective for recent onset/acute hyperacusis?

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  - Prioritisation workshop
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## Hyperacusis Priority Setting Partnership (PSP) Final workshop

**Location:** Council room, Trent Building, University of Nottingham, University Park, Nottingham, NG7 2RD

**Date:** 23rd July 2018

**Time:** 10.00 – 17.00

Attendees	No.
People with experience of hyperacusis	6
Parents/Carer	5
Audiologists	6
Clinical psychologist	3
ENT	1



- Prioritisation workshop
  - Discuss and finalise top priorities for research

### Small group discussions



### Large group discussions



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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?

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# Acknowledgements

Follow us:  
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Carolyn Farrell  
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Peter Byron



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Dr Roland Schaette

