

# How patients can help future research into a distressing hearing condition

October 23 2017, by Emma Rayner

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Credit: University of Nottingham

Researchers are calling for people who are hyper-sensitive to noise to help them decide the future of research into this little-known hearing condition.

Hyperacusis is a hearing disorder that seriously affects the lives of thousands of people who experience it. Around 8% of adults and 4% of children are diagnosed with it. It can have a serious effect on their quality of life – hindering education, working life and normal social and family interaction.

This unpleasant auditory condition involves a greatly increased sensitivity of the ears to sound and means that everyday noise can be painful and overwhelming to people affected by it. Despite its prevalence, and ongoing research, little is known about what causes it and how it can be treated.

Now hearing experts at the NIHR Nottingham Biomedical Research Centre have launched an online survey to garner the [experiences](#) and opinions of people with hyperacusis to help guide future research into the condition. The venture is a partnership with the James Lind Alliance Priority Setting Partnership with funding from the British Society of Audiology and Action on Hearing Loss.

Anyone with experience of hyperacusis can complete the survey, including carers, family, teachers, members of the public and health professionals who work with and support those who experience hyperacusis.

Leading the project, Dr Kathryn Fackrell, said: "There is a growing interest in conducting hyperacusis research and whilst this is good news, we do need to ensure that the direction this research takes is relevant and matters to those who really understand the issues and experiences surrounding hyperacusis.

"We want to make sure every voice is heard and that what matters most is turned into [priority](#) questions that will have a real and lasting impact on future research in hyperacusis. The Nottingham BRC will ensure the priority questions identified through this process are promoted and shared with funders and commissioners of research to ensure that future research in hyperacusis will make a real difference for adults and children living with hyperacusis."

Linda Stratmann, founder and co-moderator of Hyperacusis Support & Research Facebook group, said: "This Priority Setting Partnership on hyperacusis is important because the condition, for which there is still no effective treatment, is one that affects every area of life, restricting ability to pursue education, find employment and take part in social activities. There is so little public awareness that families and friends of people with hyperacusis often find it difficult to understand and offer

the support essential to provide as normal a life experience as possible. Enabling people with hyperacusis to provide clinicians with an insight into living with its restrictions is a step forward in adding to our knowledge."

Ralph Holmes, Director of Research at Action on Hearing Loss said: "Hyperacusis is a neglected condition – as a result, we don't know much about it, or about what works in treating it. This Priority Setting Partnership on hyperacusis is therefore very important in gaining insight into what matters to people affected by it, and the clinicians who treat them. These insights are invaluable in ensuring that the research community focusses on the things that really matter, and we'd encourage anyone affected by hyperacusis to take part and ensure their voice is heard."

More information on the research priority setting work is available [here](#), including a link to take part in the survey. The survey will be open for submissions until Friday 5th January 2018.

Provided by University of Nottingham

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