



Hyperacusis Priority Setting Partnership (PSP)

PROTOCOL

Version 1.0.

Date: 03/08/2017

1. Purpose of the PSP and background

The purpose of this protocol is to set out the aims, objectives and commitments of the Hyperacusis Priority Setting Partnership (PSP) and the basic roles and responsibilities of the partners therein. It is recommended that the Protocol is reviewed by the Steering Group and updated on at least a quarterly basis.

The James Lind Alliance (JLA) is a non-profit making initiative, established in 2004. It brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs). These partnerships identify and prioritise uncertainties, or 'unanswered questions', about the effects of treatments that they agree are the most important. The aim of this is to help ensure that those who fund health research are aware of what really matters to both patients and clinicians. The National Institute for Health Research (NIHR – www.nihr.ac.uk) funds the infrastructure of the JLA to oversee the processes for priority setting partnerships, based at the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), University of Southampton.

The hyperacusis PSP is supported by the JLA and funded by Action on Hearing Loss, British Society of Audiology and the National Institute for Health Research (NIHR) Nottingham Biomedical Research Centre. It is estimated that between 3.2 – 17.1% of children and 8 - 15% of the general adult population in Europe, and 6.2% of the population of the United States experience hyperacusis (National Health Interview Survey, 2014). For some people it has a



devastating effect on daily life. Despite, the prevalence of hyperacusis, and ongoing research, much is unknown and likely misunderstood. It is not clear what questions should be asked as a priority, particularly in terms of the diagnosis and treatment of hyperacusis. Hyperacusis does not have a dedicated registered charity in the UK, and as such there are limited funding streams available for hyperacusis research. It is therefore essential to identify the research priorities that are immediately relevant to people with lived experience of hyperacusis (patients and parents/carers) and healthcare professionals. These priorities will help inform researchers of the questions that are most important to people with lived experience and help inform research funders in hearing and the wider field of healthcare what they should consider funding.

At the NIHR Nottingham Biomedical Research Centre, a leading centre in hearing research, the Tinnitus and Hyperacusis team plan to develop a programme of research in hyperacusis based on the research priorities identified to ensure that the work is relevant and makes a real difference for people with lived experience of hyperacusis. In March 2017, Linda Stratmann, the founder and co-moderator of the hyperacusis Facebook group ('Hyperacusis Support and Research'), the main source of support and information for people with lived experience of hyperacusis, agreed to act as a user organisation representative of people with lived experience. With support from the NIHR Nottingham Biomedical Research Centre, the user organisation (Stratmann) and the JLA, the Hyperacusis PSP came together in August 2017.

2. Aim and objectives of the Hyperacusis PSP

The aim of the Hyperacusis PSP is to identify the unanswered questions about hyperacusis covering a wide scope: (1) causes, (2) assessment/diagnosis, (3) prevention and education, (4) service organisation and delivery (including cost, involvement of schools, attitudes etc), and (5) management (treatment, rehabilitation, self-management, interventions) from the perspectives of people (adults and children) with lived experience of hyperacusis and healthcare



professionals, and to then prioritise those unanswered questions that people with lived experience of hyperacusis and healthcare professionals agree are the most important.

The objectives of the Hyperacusis PSP are to:

- work with people with lived experience of hyperacusis and healthcare professionals to identify uncertainties about the diagnosis (assessment) of hyperacusis and the effects of hyperacusis treatments (rehabilitation and management/self-management)
- to agree by consensus a prioritised list of those uncertainties, for research
- to publicise the results of the PSP and process
- to take the results to research commissioning bodies to be considered for funding

3. The Steering Group

The Hyperacusis PSP will be led and managed by the following:

Representatives with lived experience of hyperacusis:

- ‘Hyperacusis Support and Research’ Facebook group – Founder
 - Linda Stratmann
- Carolyn Farrell
- Hillary Hodgson
- Mike Meadows
- Nic Wray
- Action on Hearing Loss charity representative
 - Tracey Pollard



ENT/audiovestibular physician representatives:

- Mr John Phillips, ENT consultant at the Norfolk and Norwich University Hospitals, Norwich
- Dr Veronica Kennedy, Consultant Audiovestibular Physician at Halliwell health and Children's Centre in Bolton Hospital, Bolton. British Society of Audiology Paediatric Audiology Interest Group member.

Audiology/hearing therapy representatives

- Prof David Baguley, Audiologist and Clinical researcher at the Nottingham University Hospital and NIHR Nottingham Biomedical Research Centre, Nottingham. British Tinnitus Association President.
- Peter Bryon, Audiologist at Hearing Aid Care, South Yorkshire. British Society of Audiology member.
- Jacqueline Sheldrake, Audiologist at the Tinnitus and Hyperacusis Centre, London.
- Dr Josephine Marriage, Audiologist and Clinical scientist at Chear (director), Cambridge.

Psychology representatives

- Rosie Kentish, Clinical Psychologist (retired), British Society of Audiology Paediatric Audiology Interest Group member.
- Carol MacDonald, Cognitive Behavioural Therapist psychotherapist and Clinical Psychology Lecturer at University of Stirling, Stirling.

The Partnership and the priority setting process will be supported and guided by:

Cochrane UK - staff

- Sarah Chapman, Knowledge Broker for Cochrane UK.



The James Lind Alliance (JLA)

- Toto Anne Gronlund

PSP Lead

- Dr Derek Hoare, Hearing Scientist at Nottingham Biomedical Research Centre, Nottingham. Chair of British Society of Audiology Tinnitus and Hyperacusis special interest group.

PSP coordinator and information specialist

- Dr Kathryn Fackrell, Hearing Scientist at Nottingham Biomedical Research Centre, Nottingham. British Society of Audiology Tinnitus and Hyperacusis special interest group member.

PSP support

- Dr Helen Henshaw, Hearing Scientist at Nottingham Biomedical Research Centre, Nottingham. Mild-Moderate Hearing Loss PSP coordinator

The Steering Group includes representation of patient/carer groups and clinicians in the field of hyperacusis and hearing¹. Researchers involved in leading and supporting the JLA project may attend the Steering Group meetings, particularly the information specialist, but will not participate in decision making.

¹ In some cases, it has been suggested that researchers are represented at this level, to advise on the shaping of research questions. However, researchers cannot participate in the prioritisation exercise. This is to ensure that the final prioritised research questions are those agreed by patients, carers and clinicians only, in line with the JLA's mission.



The Steering Group will agree the resources, including time and expertise that they will be able to contribute to each stage of the process. The JLA will advise on this.

4. The wider Partners

Organisations and individuals will be invited to be involved with the PSP as partners to ensure that the PSP process is inclusive and reaches a wide range of people with lived experience and healthcare professionals. Partners are groups or individuals who will commit to supporting the PSP by disseminating the PSP survey and helping the PSP to gather questions and uncertainties of practical clinical importance relating to the diagnosis and treatment of the health problem in question. Partners represent the following groups:

- Adults and children who have hyperacusis
- carers of those who have hyperacusis
- medical doctors, audiologists/hearing therapists, psychologists, and professionals allied to medicine with clinical experience of hyperacusis
- individuals, and groups, who support people living with hyperacusis

It is important that all organisations which can reach and advocate for these groups should be invited to become involved in the PSP. The JLA Adviser will take responsibility for ensuring the various stakeholder groups are able to contribute equally to the process.

Exclusion criteria

Some organisations may be judged by the JLA or the Steering Group to have conflicts of interest. These may be perceived to adversely affect those organisations' views, causing unacceptable bias. As this is likely to affect the ultimate findings of the PSP, those organisations will not be invited to participate. It is possible, however, that interested parties may participate in a purely observational capacity when the Steering Group considers it may be helpful.



5. The methods the PSP will use

This section describes a schedule of proposed stages through which the PSP aims to fulfil its objectives. The process is iterative and dependent on the active participation and contribution of different groups. The methods adopted in any stage will be agreed through consultation between the Steering Group members, guided by the PSP's aims and objectives. The stages adhere to the JLA process detailed in the JLA Guidebook².

Step 1: Identification and invitation of potential partners

Potential partner organisations will be identified through a process of peer knowledge and consultation, through the Steering Group members' networks. Potential partners will be contacted and informed of the establishment and aims of the Hyperacusis PSP.

Step 2: Initial launch / awareness raising³

The Steering group will discuss and decide how to officially "launch" the JLA and raise awareness. The launch can be an online event (launching JLA survey website and pages about JLA) that uses targeted partners to raise awareness of the launch and promote to people with lived experience and healthcare professionals through online avenues and promotional posters. The launch is aimed to:

² More details can be found in the Guidebook section of the JLA website at www.jla.nihr.ac.uk where examples of the work of other JLA PSPs can also be seen.

³ PSPs will need to raise awareness of their proposed activity among their patient and clinician communities, in order to secure support and participation. Depending on budget this may be done by way of a face-to-face meeting, or there may be other mechanisms by which the process can be launched.



- Identify and engage members of the hyperacusis PSP
- present the plan for the PSP
- initiate discussion, answer questions and address concerns
- identify partner organisations which will commit to the PSP and identify individuals who will represent those organisations' representatives and be the PSP's principal contacts

Step 3: Identifying treatment uncertainties

Each partner will identify a method for soliciting, from their members, questions and uncertainties of practical clinical importance relating to the diagnosis (assessment) and treatment of hyperacusis. A period of 3 months will be given to complete this exercise.

The methods for identifying uncertainties from members may be designed according to the nature and membership of each organisation (partner). These must be as transparent, inclusive and as representative as is practicable. Methods may include membership meetings, email consultation, postal or web-based questionnaires, internet message boards, or focus group work.

Existing sources of information about treatment uncertainties for patients and clinicians will be searched. These can include question-answering services for people with lived experience of hyperacusis and for healthcare professionals; research recommendations in systematic reviews, scoping reviews and clinical guidelines; protocols for systematic reviews being prepared and registrations for ongoing research.

The starting point for identifying sources of uncertainties and research recommendations is NHS Evidence: www.evidence.nhs.uk.



Step 4: Refining questions and uncertainties

The Steering Group will need to have agreed exactly who will be responsible for this stage – the JLA can advise on the amount of time likely to be required for its execution. The JLA will participate in this process as an observer, to ensure accountability and transparency.

The consultation process will produce “raw” unanswered questions about diagnosis and the effects of treatments. These raw questions will be assembled and categorised and refined by Kathryn Fackrell (PSP coordinator/information specialist) into “collated indicative questions” which are clear, addressable by research and understandable to all. Similar or duplicate questions will be combined where appropriate.

Systematic reviews, scoping reviews, and guidelines will be identified and checked by Kathryn Fackrell (PSP coordinator/information specialist) to see to what extent these refined questions have, or have not, been answered by previous research. Sometimes, uncertainties are expressed that can in fact be resolved with reference to existing research evidence – i.e. they are “unrecognised knowns” and not uncertainties. If a question about diagnosis or treatment effects can be answered with existing information but this is not known, it suggests that information is not being communicated effectively to those who need it. Accordingly, a record of these ‘answerable questions’ will be recorded and stored by the steering group and, resources permitting, methods for informing people with lived experience of hyperacusis, healthcare professionals and researchers alike, will be identified.

Uncertainties which are not adequately addressed by previous research will be collated and recorded (on a template supplied by the JLA) by Kathryn Fackrell (PSP coordinator/information specialist). This will demonstrate the checks undertaken to ensure that the uncertainties are true and have not already been answered. The Steering Group is ultimately accountable for agreeing true uncertainties and for agreeing personnel and resources to be responsible for this. The data

will be submitted to the JLA for publication on its website on completion of



the priority setting exercise, taking into account any changes made at a final workshop, in order to ensure that PSP results are publicly available.

Step 5: Prioritisation – interim and final stages

The interim and final stages of the process involve prioritising, through consensus, the identified uncertainties relating to the diagnosis (assessment) and treatment of hyperacusis. This will be carried out by members of the Steering Group and the wider partnership that represents people with lived experience of hyperacusis and healthcare professionals.

- The interim stage, to proceed from a long list of uncertainties to a shorter list to be discussed at the final priority setting workshop (e.g. up to 30 uncertainties), may be carried out over email or online, whereby organisations consult their membership and choose and rank their top 10 most important uncertainties. There are examples of how other PSPs have achieved this at www.jla.nihr.ac.uk in the Key Documents of the [Anaesthesia and Perioperative Care PSP](#) section and the [Childhood Disability PSP](#) section.
- The final stage, to reach, for example, 10 prioritised uncertainties, is likely to be conducted in a face-to-face meeting, using group discussions and plenary sessions.
- The precise methods used for this prioritisation process will be determined by consultation with the partner organisations and with the advice of the JLA Adviser. Methods which have been identified as potentially useful in this process include: adapted Delphi techniques; expert panels or nominal group techniques; consensus development conference; electronic nominal group and online voting; interactive research agenda setting and focus groups.

The JLA will facilitate this process and ensure transparency, accountability, and fairness.

Participants will be expected to declare their interests in advance of this meeting.



6. Dissemination of findings and research

Findings and research

It is anticipated that the findings of the Hyperacusis PSP will be reported to funding and research agenda setting organisations such as the NIHR and the major research funding charities. Steering Group members and partners are expected to develop the prioritised uncertainties into research questions, and to work to establish the research needs of those unanswered questions to use when approaching potential funders, or when allocating funding for research themselves, if applicable.

Publicity

As well as alerting funders, partners and Steering Group members are encouraged to publicise the findings of the Hyperacusis PSP using both internal and external communication mechanisms. The Steering Group may capture and publicise the results through descriptive reports of the process itself in Plain English. This exercise will be distinct from the production of academic papers, which the partners will pursue. Production of an academic paper will not take precedence over publicising of the final results.

7. Agreement of the Steering Group

Approved by the Steering Group

This protocol was approved by the Steering Group on Wednesday 23rd August 2017.