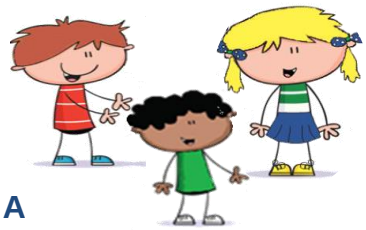
# Hyperacusis in children questionnaire



**Tell us your observations of hyperacusis in children and help us develop a questionnaire!**

## Part A

### About the study

- **Hyperacusis** is a long-term condition commonly defined as a reduced tolerance to sound(s) that are perceived as normal by the majority of the population or were perceived as normal by the child before the onset of hyperacusis.
- **The purpose** of this study is to develop a questionnaire measure of hyperacusis in children.
- The data collected will help us to develop and test the new questionnaire. The findings will also tell us if we need to make any improvements.
- The study will involve 3 phases:

1- creating questionnaire questions using interviews,

2- questionnaire development using a focus group and further interviews, and

3 – testing out the questionnaire with a large population of parents/guardians

### 1 - Interviews with clinicians

- We are currently looking for clinicians who manage children with hyperacusis to take part in a 1-hour one-to-one interview.
- We will discuss they way in which hyperacusis affects children's well-being and development and their relationships with others.

### Who can take part?

You can take part if you are a clinician who has experience of managing children aged 2-7 years who present with hyperacusis.

### Why have I been invited to take part?

- You are being invited to take part because you have been identified as a care provider for children with hyperacusis.

### Why take part?

- By taking part, you will help us to develop a clinical questionnaire that will be used to assess children with hyperacusis. The questionnaire may help healthcare providers decide how best to treat a child with hyperacusis.

## Part A Continued

### What will happen to me if I take part?

- Taking part in this phase of the study will involve an up to 60-minutes discussion as part of a one-to-one interview.
- This can be conducted over the phone, virtually via MS Teams or face-to-face if you are based in Nottingham.
- The focus group will be facilitated by the Study Co-Ordinator, Iskra (Part C).

### Disadvantages of taking part

- We do not envisage any disadvantages of participating in this phase of the study other than the burden of time.

### Do I have to take part?

- It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

### What will happen if I don't want to carry on with the study?

- Your participation is voluntary, and you are free to withdraw from the study at any time, without giving any reason and without your legal rights being affected.

### What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting Faculty of Medicine and Health Sciences Ethics: fmhs-researchethics@nottingham.ac.uk

In the event that something does go wrong, and you are harmed during the research, and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

### For more information or to take part:

Email: Iskra.Potgieter@nottingham.ac.uk

Mob: 07859080009

**Part B**

## Confidentiality & Data Protection

- All interview and focus group discussions will be audio recorded. Questionnaire data will be coded and stored into a secure digital database.
- All data will be anonymised using a study identification number and kept confidential.
- If you decide to withdraw, no further information will be collected. However, it will not be possible to erase the information already collected, and this information may still be used anonymously in the project analysis.

### Will my taking part in this study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.
If you participate in the study, we will use information collected about you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (Derek Hoare) is the Data Custodian (manages access to the data). This means we are responsible for looking after the information and using it properly. Rights to access, change or move your information are limited as we need to manage the information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally – identifiable information possible.
You can find out more about how we use your information and read our privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.
All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database

Audio recordings will be destroyed immediately after anonymous transcription. Your personal data (address, telephone number) will be kept for 12 months after the end of the study. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality. Only members of the research team will have access to personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information, we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

**Part C**

## Meet the team


**Iskra Potgieter (PhD Student) – Study Coordinator**

Iskra. Potgieter@nottingham.ac.uk
Tel: 07859080009


*I am responsible for coordinating all phases of research project. I will conduct the individual interviews, facilitate the focus group and collect questionnaire data.*

*My wider team includes my academic supervisors, Dr Derek Hoare and Dr Kathryn Fackrell, and clinical advisors, Dr Claire Benton, Dr Veronica Kennedy, Dr Zara Jay, Dr Sudhira Ratnayake and Dr Shameela Munir.*


**Derek Hoare – Chief Investigator**

Derek.Hoare@nottingham.ac.uk
Tel: + 44 (0) 115 82 32630


The research team are happy to answer any questions you have before or during your participation in the project.

## Who is organising and funding the study?

This project is funded by the National Institute for Health Research (NIHR) Nottingham Biomedical Research Centre and University of Nottingham.

## Who do I speak to if problems arise?

Our staff always try to conduct research in a way that is caring and respectful. If you do have any concerns about any aspect of the study, you should contact:

Chief Investigator: Derek Hoare

- Email: Derek.Hoare@nottingham.ac.uk
- Tel: + 44 (0) 115 82 32630

## Who has reviewed the study?

This study has been reviewed and given favourable opinion by:

- ✓ Research Ethics Committee [21/SC/0419]
- ✓ The Study Sponsor (University of Nottingham) and Nottingham University Hospitals NHS Trust Research and Development.