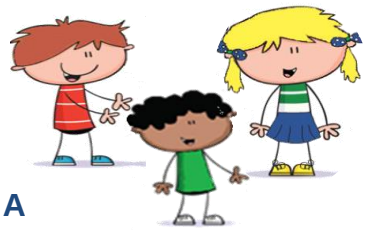
Hyperacusis in children questionnaire



Did you know? You can help develop a questionnaire for hyperacusis in children!

Part A

About the study

- **Hyperacusis** is a long-term condition defined as a reduced tolerance to sound(s) that are perceived as normal by the majority of people
- **The purpose** of this study is to develop a questionnaire 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

2 - Further interviews with parents

- We are currently looking for the parents of children with hyperacusis to take part in a further interview.
- The aim is to test the newly developed questionnaire and discuss how it can be improved.

Who can take part?

You can take part if you are a parent/ guardian of a child:

- aged 2-11 years,
- has seen a healthcare provider about hyperacusis

Why have I been invited to take part?

You are being invited to take part because your child's care provider has identified you as fitting the criteria for the study.

Why take part?

We cannot promise that the study will help your child, however by taking part, you will help us to develop a clinical questionnaire that will be used to assess children with hyperacusis

To take part contact Iskra on 07859080009
Iskra.Potgieter@nottingham.ac.uk

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-minute discussion as part of a one-to one interview. You will be asked to complete the newly designed questionnaire and comment on its clarity and ease of use.
- This can be conducted over the telephone, virtually via MS Teams or face-to-face, if you are based in Nottingham.
- The interview will be led by the Study Co-Ordinator, Iskra (Part C).

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, without giving a reason and without your child's care being affected. 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 child's care being affected.

Disadvantages of taking part

It is possible that you may find discussing your child's hyperacusis upsetting. To prevent this, we have designed the interview discussion guides to approach topics in a sensitive manner. If it becomes challenging for you to speak about your child's experiences, the interviewer will utilise projective/ "third person" techniques that encourage you to suggest the feelings and attitudes of other children with hyperacusis to the situation being discussed.

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

If you are an NHS patient, you can contact the Patient Advice and Liaison Service (PALS):

Please call Freephone: 0800 183 0204 (free from a UK landline) or from a mobile or abroad: 0115 924 9924 ext: 65412 or 62301 Email: pals@nuh.nhs.uk.

Or you can write to: NUH NHS Trust, c/o PALS, Freepost, NEA 14614, Nottingham NG7 1BR

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 and Dr Sudhira Ratnayake.

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.