**PARTICIPANT INFORMATION SHEET GUIDANCE**

### Section A: The Research Project

1. **Research Title: A pilot study to explore parental management of Hyperacusis in children.**
2. **Purpose of study**

This study is designed to explore parental management strategies of paediatric hyperacusis. Hyperacusis is the intolerance to everyday sounds that causes distress and affects day-to-day activities.

1. **Who is the researcher?**

Dan Walker, BSc Audiology student. The project is supervised by Bhavisha Parmar, Tutor and Researcher at Anglia Ruskin University. This study is part of an undergraduate degree.

1. **Why have I been asked to participate?**

You have been asked if you would like to participate as you are a parent of a child with hyperacusis, based in the UK.

1. **How many people will be asked to participate?**

This is a pilot study, and we are looking for 20-50 parents to participant

1. **Do I have to take part?**

You have no obligation to take part in this study and if you do wish to participate, you can withdraw at any point, without providing a reason.

1. **Has the study got ethical approval?**

Yes, the study has ethical approval from the Faculty of Science & Engineering Research Ethics Panel committee at Anglia Ruskin University

1. **Has Anglia Ruskin University given permission for this study?**

Yes, Anglia Ruskin University

1. **Source of funding for the research, if applicable**

No funding.

1. **What will happen to the results of the study?**

The research data collected will be treated confidentially and stored securely. Please see the [Anglia Ruskin University Privacy Notice](https://aru.ac.uk/privacy-and-cookies/research-participants) for further details.

All data will be anonymised and the research will be disseminated via conferences and journal publications. No personally identifiable data will be stored, the data will be kept securely in a controlled environment on Anglia Ruskin University’s intranet as per the GDPR guidelines. The dataset will be kept until dissemination is complete and then stored in a data repository.

1. **Contact for further information**

### For further information contact Ms Bhavisha Parmar, Audiologist and Tutor at Anglia Ruskin University, Department of Vision and Hearing Sciences ([Bhavisha.parmar@aru.ac.uk](mailto:Bhavisha.parmar@aru.ac.uk)) Section B: Your Participation in the Research Project

1. **What will I be asked to do?**

You will be asked to answer questions on your management strategies to help your child with their hyperacusis. The survey will take approximately 10 minutes.

1. **In relation to this specific research project, we need to make you aware of the following:**

*Please note that Sections 2 and 3 are only mandatory if your research needs to comply with GDPR (by virtue of the nationality of the participants or the location where personal data was obtained or where the analysis will be undertaken). If it doesn’t apply it would still be best practice to use the below text, in order to fully inform the participant but you must be aware of any relevant legislation relating to countries outside the European Economic Area and comply with it*.

|  |  |  |  |
| --- | --- | --- | --- |
| ☐ | We do not need your personal data at any stage of this research project | | |
| We are responsible for the personal data you give to us as a: | | | |
| Y | **Data Controller**  (We are in sole control over the research) | Who are we?: | Anglia Ruskin University:  Daniel Walker, BSc Audiology Student.  Bhavisha Parmar, Audiologist and lecturer at Anglia Ruskin University. |
| N | **Joint Controller**  (Where ARU and another organisation are working together on research) | with: |  |
| N | **Data Processor** (Where the data will belong to another organisation and ARU is being engaged under contract/ agreement to conduct the research and provide an outcome but has no rights over the personal data) | on behalf of: |  |

1. **I will be asking you for the following information:**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Personal Data** | | | | **Sensitive Personal data** | |
| ☐ | Name/Contact details | ☐ | Image (photo or video) | ☐ | Racial/Ethnicity data |
| Y | Age | Y | Experiences | ☐ | Political/Religious beliefs |
| ☐ | Address/location data | Y | Opinions | ☐ | Trade Union membership |
| ☐ | Employment & Earnings | Y | Age | ☐ | Genetic/Biometric data |
| ☐ | ID Numbers (e.g. NHS) | ☐ | [Other] | ☐ | Health |
| ☐ | Online identifier | ☐ | [Other] | ☐ | Sex life/orientation data |

1. **What will happen to your data?**

In accordance with data protection law, Anglia Ruskin University is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

Your data will be anonymised by removing all personal identifiers that may lead to you being identified from that information or combined with other information. Access to the information will require the use of passwords. Only the researcher team will have access to the information. Answers from all participants will be grouped together, analysed and presented in summary so no one will know your individual answers. The research data will remain in the European Economic Area (EEA) and held securely at Anglia Ruskin University.

The research findings will be disseminated in conference presentations and journal articles. We may use anonymised quotes from the survey in the dissemination**.** This survey is being hosted by JISC Online Surveys which participates in and has certified its compliance with the EU-U.S. Privacy Shield Framework. Details of their privacy policy can be viewed here: <https://www.jisc.ac.uk/website/privacy-notice>

1. **Will I be reimbursed travel expenses?**

This is an online survey, therefore travel is not required.

1. **Will I receive any payment to take part in the research?**

There is no payment for taking part in this research study

1. **Are there any possible disadvantages or risks to taking part?**

Apart from boredom and fatigue, there are no other risks. The study team can be contacted any time via email. Agreement to participate in the study does not affect your legal rights.

1. **What are the likely benefits of taking part?**

The main benefit is the educational benefit to our research team and this will help us plan future research investigating hyperacusis in children

1. **Can I withdraw at any time, and how do I do this?** During the survey, participants can withdraw from the study at any time and without giving a reason, by closing the survey window. If you complete the survey, you cannot withdraw from the study as the data collected from you was anonymous. This means that I won’t be able to remove your data, because I won’t know which belongs to you.
2. **What will happen to my data?**

|  |
| --- |
| **Our general privacy notice explaining our use of your personal data for research purposes is available here:**  <https://www.aru.ac.uk/privacy-and-cookies/research-participants>  **Please visit this link for information about how long we keep your data, how we keep your data secure, how you can exercise your rights over your data, and make a complaint over our use of your data.** |

1. **Whether there are any special precautions you must take before, during or after taking part in the study**

There are no precautions to take before, during or after taking part in the study

1. **Will I pass onto anyone else what you have told me?**

We will not pass on information to anyone else and as the data collection process is anonymous we will not have access to your personal details to identify you.

1. **Summary of research findings**

If you would like a summary of the group research findings you can request this from the research team.

1. **Contact details for complaints**

If you have any complaints about the study, please do contact Bhavisha Parmar , in the first instance

You can also contact our complaints department with the contact details below.

Email address: [complaints@aru.ac.uk](mailto:complaints@aru.ac.uk)

Postal address: Office of the Secretary and Clerk, ARU, Bishop Hall Lane, Chelmsford, Essex, CM1 1SQ. You also have a right to complain to the [Information Commissioner’s Office](https://ico.org.uk/make-a-complaint/) about complaints relating to your personal identifiable information (Tel 0303 123 1113).

PARTICIPANTS SHOULD BE GIVEN A COPY OF THIS TO KEEP,

TOGETHER WITH A COPY OF THE CONSENT FORM.

Date 17 September 2019

V1.15

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