



The FUN Study - Fatigue in Unilateral Hearing Loss

Clinician Information Sheet

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Why is this project important?

Fatigue is a known problem in children with hearing loss, including children with hearing loss in one ear only (**Unilateral Hearing Loss; UHL**).

The nature of fatigue in children with UHL and the reason why they experience this fatigue is not yet known.

By taking part in these studies, you will be able to give insight on fatigue and its potential affects in routine care.

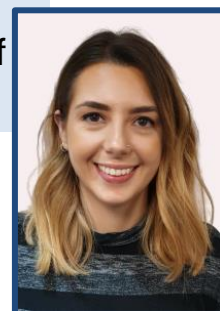
For more information or to take part

Email: bethany.adams@nottingham.ac.uk

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Who am I?

My name is Bethany Adams. I am a PhD student studying fatigue and unilateral hearing loss (UHL) in children at the University of Nottingham.



1 Why are we doing the FUN Study?

- The nature of fatigue in children with UHL, and how/if it differs to children with hearing loss in both ears (bilateral hearing loss; BHL) or children with normal hearing (NH) is unknown.
- The reasons behind this fatigue in children with UHL is also unknown.
- Fatigue is also difficult to measure in children, especially children with a hearing loss.
- This project aims to help us understand fatigue in children with hearing loss, why children with hearing loss experience fatigue and review current measures of fatigue.
- Understanding more about this may provide insight on possible future treatments to reduce or help children to cope with fatigue.

2 Who can take part?

- You can take part if you are a clinician or educational provider who is currently managing children with unilateral hearing loss.

See separate information sheet regarding children's and parent's discussions

3 What does taking part involve?

- The discussion will be conducted by the Study Coordinator (see section 9).
- It will take 30-60 minutes and will either be conducted remotely (over telephone/skype) or at Ropewalk House.
- We will talk about the assessment of UHL and related fatigue in routine care, parents concerns about fatigue, potential solutions for fatigue and treatment effects.

Will I benefit from taking part?

You will not directly benefit from taking part in this study.

4 Why take part?

- This research may help to improve our understanding of fatigue in children with unilateral hearing loss.
- By taking part you will be helping us to understand more about fatigue and its effects from a professional point of view.
- This research may provide insight on possible future treatments to reduce fatigue in children with UHL.

5 What will happen if I don't want to carry on with the discussion?

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

6 Confidentiality & Data Protection

- All discussions will be video or audio recorded so data can be analysed afterwards.
- All information will be kept confidential and opinions and experiences will be anonymised in the research results.
- 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 (Padraig Kitterick) 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

6 Confidentiality & Data Protection

Continued...

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.

7 Who has reviewed the project?

This study has been reviewed and given favourable opinion by:

- ✓ **HRA and HCRW** Research Ethics Committee.
- ✓ The Study Sponsor (University of Nottingham) and Nottingham University Hospitals NHS Trust Research and Development.

8 Who do I speak to if I have concerns about the project?

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: Pádraig Kitterick

- Email: padraig.kitterick@nottingham.ac.uk
- Phone: 0115 8232626

9 Meet the team



Bethany Adams
(PhD Student) – Study Coordinator

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This study is part of my PhD research project titled "**The Basis of Fatigue in Children with Unilateral Hearing loss**".

I am responsible for coordinating the study and will be conducting the all elements of the study.

My wider team includes my supervisors, Pádraig Kitterick, Sally Thornton, Ian Wiggins and Graham Naylor.



Pádraig Kitterick
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