

# The COACH trial

## A randomised controlled trial of cochlear implantation versus hearing aids in adults with severe hearing loss

We invite you to apply to join us as a trial steering committee member

### What is this study about?

In the UK, a cochlear implant may be offered if an adult can only hear volumes of 80 decibels and above. We don't know if adults who have slightly better hearing would get more benefit from hearing aids or a cochlear implant.

We want to know if adults who can hear lower volumes, down to 70 decibels should be offered a cochlear implant. We will run a clinical trial to find out.

### Why do we need you?

Researchers may not know what it is like to live with hearing loss nor listen through hearing aids or cochlear implants. Your life experience relating to hearing loss is invaluable. We need you to advise the researchers on:

- When and how to approach people who could take part.
- What people will need and want to know before taking part.
- How to keep participants informed during the trial.
- Issues that might arise during the trial.
- Making sense of the data collected.
- How to share the results with professionals and the public.

### What are we inviting you to do?

- We would like you to apply to join the trial steering committee for the study as a public research partner.
- The trial steering committee is the executive body that has overall oversight of the trial.
- The trial steering committee meets annually to review study progress. This will be online but you could meet some members in person, COVID-19 allowing.
- No training is necessary but experience of contributing to meetings is desirable.
- The study will last for 4 years.

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### How to contact us

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If you have any questions, please contact either:

Di Matthews, who is our lead patient representative:

[dleeb666@msn.com](mailto:dleeb666@msn.com)



or Dr Adele Horobin who is our public involvement lead

[adele.horobin@nottingham.ac.uk](mailto:adele.horobin@nottingham.ac.uk)



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## 1 Who are Public Research Partners?

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Members of the public who draw upon their own life experience in a partnership with researchers. Together, they design and deliver research that is relevant, and built around, the needs of patients.

You do not require any formal qualifications and you do not need any prior experience of research.

### Key attributes for Public Partners:

1. An interest in research to improve healthcare.
2. Willing to spend time getting to understand the information given.
3. Able to express one's thoughts.
4. Confidence to ask questions, challenge the use of jargon and acronyms.
5. Appreciate the valuable contribution that public partners can make.
6. Commitment to equality and diversity
7. Able to see things from a broader perspective.
8. Happy to draw upon own experiences and knowledge of others' experiences.

### Experience important for this role

- You will be guided by your own experience of severe hearing loss, as a patient and/or a carer or communication partner, or who represents the views of patients.
- Prior experience of contributing to meetings is desirable.
- It would be ideal if you were comfortable in using online meeting platforms or willing to have a go (we will offer you support: see 3).

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## 2 Your role in this work

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- Your voice for the patient will keep conversations focussed on what matters to patients.
- Being on the trial steering committee is different to being involved in the day-to-day running of the study. See below.

### What is a trial steering committee?

It is the executive body that has overall oversight and supervision of the trial.

It offers governance – reviewing progress towards defined goals on a pre-agreed timescale.

It also reviews patient safety and considers any new information relevant to the study.

Each member brings their own specialist expertise.

This includes public, or lay, members of the committee who bring their expertise gained from lived experience of the health condition.

The chair and some other members of the committee are independent from the study and not from the same institution.

The chief investigator who runs the study will be a member of the committee to report on progress and act on recommendations.

- We plan to have two public members on the trial steering committee, one of whom could be you!

### What are we inviting you to do?

- You shall be a full member of the trial steering committee.
- You shall contribute to annual (yearly) meetings where study progress is presented and advice given in return.
- Annual meetings will occur over 4 years.

- Before a meeting, you may be asked to read material in advance. Data may be included in this, but we can explain anything if you would like this.
- We shall stay in contact by email.
- Meetings will be held online. If you would prefer face-to-face support, you may have the option to join some Committee members in-person at Nottingham when meetings are held. This depends on COVID-19 guidance.

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### 3 What support can you expect?

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We are aware of how difficult online meetings can be for people who have severe hearing loss. We will do all that we can to support you in taking a full part in meetings, such as:

- Ensuring you have access to live captions.
- Highlighting who is speaking so it is easier to keep track.
- Timetabling frequent breaks as listening can be tiring.
- Advising all meeting participants to speak one at a time and not to rush.
- Signalling when we are moving on to the next topic.
- Coaching you in getting set up and becoming familiar with online meeting software.

If you have specific requirements to aid reading any material (large font for example), we will endeavour to provide this.

We can reimburse reasonable expenses associated with attending meetings, including an online meeting reimbursement fee. Currently, we cannot book any travel but we are hoping, when current COVID restrictions are relaxed, we should be able to book train tickets on your behalf for face-to-face meetings.

We also offer honorary payments for your involvement, in line with our internal payments policy and national guidance. For information

about if or how these payments affect state benefits you may be receiving, you can contact the 'Benefits Advice Service for involvement for members of the public':

[www.invo.org.uk/benefits-advice-service-for-involvement-for-members-of-the-public/](http://www.invo.org.uk/benefits-advice-service-for-involvement-for-members-of-the-public/). For tax implications, the following may be useful: <http://www.invo.org.uk/payment-resources/tax-and-national-insurance/>. We cannot advise you on these matters.

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### 4 Who is funding this work?

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It is funded by an industry grant from Cochlear Ltd, a company who make cochlear implant devices. The study is run by NHS Doctors, NHS Audiologists, and researchers from the [University of Nottingham](http://www.nottingham.ac.uk), without the company being involved. The contract clearly specifies Cochlear Ltd cannot influence trial conduct, data analysis or publication of results.

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### 5 Who will you work with?

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You will work closely with other members on the trial steering committee. You may also have contact with Dr Adele Horobin, public involvement lead for the [Nottingham Biomedical Research Centre](http://www.nottingham.ac.uk/biomedical-research-centre), to check whether you require any extra support or guidance.

#### Who is leading the study?

- Dr Pdraig Kitterick, academic lead and Chief Investigator.
- Prof Gerry O'Donoghue, and Prof Doug Hartley, clinical leads.

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## 6 How do I apply to join the trial steering committee?

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We are ideally looking for two members who together shall provide a mix of perspectives and life experiences of hearing aids and cochlear implants. It may be that we invite someone who uses a cochlear implant and someone who uses only hearing aids; or that we include someone who is a communication partner to a deafened individual and/or has experience advocating for people with hearing loss.

To help us, please tell us a little bit about yourself, including what your interests are in hearing loss, whether you use a cochlear implant and/or hearing aids, whether you work or are retired and what you would like to get out of the role. Also please let us know if you have taken part in research before and if you have contributed to meetings previously as well. Thank you. You can include a few sentences in an email to us.

To send us your application, or for further enquiries about the role, please email us at:

[adele.horobin@nottingham.ac.uk](mailto:adele.horobin@nottingham.ac.uk)

Your application will be considered by the following members on the research team:

- Ms Diane Matthews, public member of the trial management team and cochlear implant user
- Dr Adele Horobin, public involvement lead for the Nottingham Biomedical Research centre Hearing theme
- Dr Cally Rick, public involvement lead for the Nottingham Clinical Trials Unit
- Ms Hayley Gregory, Clinical Trials Manager
- Dr Pdraig Kitterick, chief investigator for the trial.

Please express your interest for the role by **16 April 2021**. Thank you.

We shall endeavour to let you know the outcome by 7 May 2021.

If we aren't able to offer you a position on the group, we will welcome you to contribute to the trial in other ways or help with other research.

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## 7 Data Protection

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By submitting your application and/or contact details, you are providing your consent for us to use that information to help us in deciding who to invite to join the Trial Steering Committee. Your information will be stored securely and will not be shared with anyone outside of the COACH research team.

We will only hold information which you put in your application until we have confirmed membership of the trial steering committee. It will then be destroyed. The only exception to that would be if you have indicated that you would be happy for us to keep your information on file should we need replacement trial steering committee members at a future date during the four-year study. After that, your information will be destroyed.

Please see the University of Nottingham Privacy Notice which explains how your personal data is processed and the rights you have with respect to your personal information: <https://www.nottingham.ac.uk/utilities/privacy/privacy.aspx>.

Specific information on the purposes for which your data is processed and the legal bases for this is available at <https://www.nottingham.ac.uk/utilities/privacy/privacy-information-forresearch-participants.aspx>