Deaf & Hard of Hearing
FOUNDATION
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Listen Up, New Zealand:
Participant Information Sheet

Risk of non-occupational Noise Induced Hearing Loss (NIHL) in New Zealand adolescents

Ethics committee reference

20/NTA/72

Lead investigator:

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Contact phone numbers:

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Introduction

You are invited to take part in the Listen Up, New Zealand study, led by the National Foundation for the Deaf and Hard of Hearing (NFDHH). This study aims to understand hearing loss trends in young New Zealanders and how personal listening habits may impact hearing health. Please read this information carefully and feel free to ask any questions before deciding whether your child will participate.

Purpose of the study

Globally, 1 in 5 teenagers have some form of hearing loss and this number is predicted to double over the next 30 years. A major factor in youth hearing loss is ongoing exposure to loud noises, such as listening to personal devices on headphones too loudly and/or for too long. Research suggests that hearing loss among New Zealand youth may align with these global trends. Noise-induced hearing loss is irreversible but preventable.

To raise awareness among young people about the risks to their hearing, the National Foundation for the Deaf and Hard of Hearing established its Hearing Screening Programme in 2019. The initiative delivers hearing health education and offers free screenings in selected secondary schools across New Zealand. Screening outcomes contribute to ongoing monitoring, providing vital data on the prevalence of hearing issues among New Zealand youth. Early identification of hearing loss in young people is essential to ensure they can access the support they need—both at school and as they move into employment—without impacting their future.

This Listen Up, New Zealand, study has been approved by the Health and Disability Ethics committee as of 29 July 2020 (reference number 20/NTA/72). The National Foundation for Deaf & Hard of Hearing pays for the study.

What will participation in the study involve?

- Participation in the study involves attendance at one hearing screening test and completion of a questionnaire. The total duration will be up to 30 minutes.
- Undergo a free non-invasive hearing screening at school using HearX digital testing. This will involve your child wearing a headset and listening to sounds at different frequencies (between 500hz and 6000hz) and volumes (25-30db).
- Potentially be asked if the tester can look in their ears for wax using as otoscope.
- They will also complete a questionnaire, spending approximately 3-10 minutes on the entire screening process.
- Demographic information as well as information about the students' hearing and music listening habits will be recorded through the questionnaire. There are no good or bad answers, and the responses to the questionnaire do not influence the screening.
- Receive a referral for a free full diagnostic hearing test if a hearing issue is detected.

While screening tests are simple, they are not thorough. This may result in missing a hearing problem. If you have concerns about your child's hearing you should take them to have a full diagnostic hearing test, even if you have had a normal hearing screening test.

What are the possible benefits and risks of this study?

Risks: There are no known risks, side effects, or health concerns associated with this study. If you or your child have any concerns, please contact the school or the study team.

Benefits:

- Early detection of a hearing issue in your child, allowing for timely intervention.
- Contribution to research aimed at protecting young people's hearing health in New Zealand.

Are there any costs involved in participating, and/or will participants receive any payment

Participants will not incur any costs or receive any payments as part of this study.

What if something goes wrong?

If a participant were to get injured in this study, they would be eligible to apply for compensation from ACC similar to an accident at work or at home. This does not mean that a claim will automatically be accepted. To apply, a claim has to be lodged with ACC, which may take some time to assess. If the claim is accepted, you will receive funding to assist in your recovery.

What are my rights?

Participation in this study is entirely voluntary and you or your child may decline to participate or withdraw from the research at any time without experiencing any disadvantage.

- You have the right to access any information you collected as part of the study at any point.
- You can request access to your child's study information at any time.
- You will be told of any new information about adverse or beneficial effects related to the study that becomes available during the study that may have an impact on your child's health.

Confidentiality and Data Storage

The protection of your confidential personal information is of utmost importance to the National Foundation for Deaf & Hard of Hearing. The specifics of our privacy policy are attached for your reference. In brief, the privacy policy states that only you, your child, the researchers, the Foundation Chief Executive and anyone that you or your child give the authorisation to access your, and your child's, data (including the questionnaire and test results) at any time. The National Foundation for Deaf and Hard of Hearing is not allowed to use your data for any other purpose than for this study, according to the Privacy Act 1993. Data will be stored by the Foundation on a secure cloud server (located in Australia) that only the Chief Executive has access to, for a maximum of 10 years.

If any hearing loss is detected, the school will be informed by default so that they can provide further support. You may choose to have results sent directly to you instead.

What happens after the study or if I change my mind?

If a hearing loss is recorded, NFDHH will prepare a referral letter, which is then provided to the school contact (Nurse or Deputy Principle) and sent to parents/guardians directly. This referral letter will advise you of any further action required.

If required, the NFDHH can make the results of the original screening available to medical professionals involved in the full hearing assessment.

Aggregated results of the study will be made available to the general public, including you and your child. At no point will this include any personal identifiable information.Who do I contact for more information or if I have concerns?

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This study has been reviewed and approved by the Health and Disability Ethics Committee (HDEC).

If you have any questions about the study, please contact:

- **Natasha Gallardo – Chief Executive, NFDHH**
  Phone: 09 307 9222 | Email: natasha@nfdhh.org.nz

For independent advice about participation, contact:

- **Health & Disability Advocacy Service**
  Phone: 0800 555 050 | Email: advocacy@advocacy.org.nz | Website: www.advocacy.org.nz

For Māori health support, contact:

- **HealthCare New Zealand**
  Phone: 0800 227 348

For ethics-related concerns, contact:

- **Health & Disability Ethics Committee (HDEC)**
  Phone: 0800 4 ETHICS | Email: hdecs@moh.govt.nz