

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:

0800 867 446

What is the 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.

Here in New Zealand, we are also starting to see alarming levels of youth hearing loss and our initial hearing screenings at secondary schools indicate that our youth hearing loss rates could be mirroring global trends.

Noise-induced hearing loss is irreversible and completely preventable. To ensure young people are aware of the risks, the National Foundation for the Deaf and Hard of Hearing launched a Hearing Screening Programme in 2019, which focuses on educating young people and provides free hearing screenings at selected secondary schools throughout New Zealand.

The hearing screening results will form part of an ongoing tracking and monitoring programme, which will provide essential data on youth hearing prevalence rates in New Zealand.

It is important that youth hearing loss is picked up, as early as possible, and that students can access the support services they need so that their hearing loss doesn't hold them back at school or as they transition into their first job.

In 2025 **your school will** be participating in the National Foundation for Deaf and Hard of Hearing (NDFHH) Hearing Screening Programme. NDFHH will provide free hearing screening checks for all year 9 students, and collect information from students on their environment and use of personal listening devices. The programme is aimed at helping the NDFHH understand the prevalence of hearing loss in young New Zealanders.

NDFHH will provide audiometric testing either using HearX digital hearing screening or technicians employed by Proactive/WOHC, who are specialised in performing industry-standard audiometric testing. NDFHH will also provide students with a questionnaire about their personal device listening habits.

This 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?

Why has your child been chosen to participate?

All year 9 students at selected schools will be invited to participate. These schools have been selected to provide a representative view of New Zealand youth.

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.

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.

If we identify hearing loss with participants, we recommend that they proceed to have a full diagnostic hearing test.

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?

Are there any risks, side effects or discomforts associated with participating in this study?

There are no risks or side effects associated with participation in this study. To accommodate potential concerns around having hearing loss, students and/or their parents/guardians can contact the school and/or the contact persons at the end of this document.

Does participation pose any risk to the health of the participant and/or family members?

There are no health risks to the participant or family members.

What are the possible benefits of participating in this study?

For the participant, the study might identify any hearing loss, which would otherwise not be identified. Early identification can minimise the impact.

For the Foundation for Deaf and Hard of Hearing, the study will improve the understanding of the extent and prevalence of hearing loss in adolescents 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 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.

The protection of your confidential personal information is of utmost importance to us and to our audiometric testing provider, Proactive/WHOHC. 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. After the initial assessment of screening results by Proactive/WHOHC, they will not store any identifiable data.

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?

If you or your child have any questions, concerns or complaints about the study at any stage, you can contact:

Name: Natasha Gallardo – Chief Executive position

Telephone number: 09 307 9222

Email: natasha@nfdhh.org.nz

If you or your child want to talk to someone who is not involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050

Fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@advocacy.org.nz

Website: <https://www.advocacy.org.nz/>

For Māori health support please contact :

Name: HealthCare New Zealand

Telephone number: 0800 227 348

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS

Email: hdecs@moh.govt.nz