

# 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:

Natasha Gallardo

### Contact phone numbers:

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### 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 2024 **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/WOHC. 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/WOHC, 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](mailto: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](mailto: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](mailto:hdecs@moh.govt.nz)*

## Listen Up, New Zealand: Study Protocol

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

#### Literature Review

New Zealand data on the incidence of hearing impairment in the under-24 age group ranges from 10% to 15% (categorisation as available in Statistics New Zealand and Listen Hear New Zealand report, 2018). The disability survey 2013 data suggests 1% of children up to the age of 14 and 2% of 15 to 44 years olds experience moderate to severe hearing loss (the incidence rising to 34% of men and 23% of women over the age of 65). The incidence of hearing impairment from all causes is higher amongst ethnic minorities such as Maori and Pasifika people, and socioeconomically deprived sections of New Zealand society, even after adjusting for confounders. The Deafness Notification Database report of 2017 further confirms this, reporting most of the 1561 notifications of deafness since 2010 were from high deprivation areas (NZDep 2013 scores of 8, 9 and 10). Initially managed by the National Audiology Centre (NAC), the database was, until 2005, the only source information on the number of New Zealand children diagnosed with different types of hearing impairments. It was launched again in 2010 by the New Zealand Audiological Society to prevent any missed cases for the purposes of planning and accurate monitoring of trends. Its 2017 report lists 1561 newly diagnosed cases of hearing loss in children from birth to 18 years of age since 2010, when the database was relaunched. The Ministry of Health's Well Child/Tamariki Ora programme funds comprehensive health checks, including hearing screening, for four-year olds. The B4School Check (MoH, 2019) compliments the new-born hearing screening conducted just before a child goes home from hospital/delivery rooms and the two are meant to pick up any hearing impairment early and provide treatment. The above two screening programmes do not take into account the enhanced risk of impairment among adolescents and youth during their school years due to health and lifestyle factors including infections, lack of immunisations, injury or exposure to loud music for extended periods. In 2000, Northland District Health Board began a comprehensive health and lifestyle screening of year 9 students from low decile schools in the region. The HEEADSSS (Home environment, Eating and exercise, Education/employment, Activities, Drugs and Alcohol, Sexuality, Suicide and mood, Safety) programme found some evidence of this hearing loss, but did not take into account the degree of loss and the causes thereof, or the strategies to address them before the youth leave school and enter the workforce. Under the HEEADSSS programme, 1830 students were screened, of which 56 (3.05%) were referred to either an audiologist or an ear nurse for failed audiogram or tympanometry test (HEEADSSS, 2000).

#### *Cost to the health system*

Unaddressed hearing loss poses huge costs to the healthcare system and to the economy as a whole. Academic and/or learning difficulties, bullying, mental health problems, low employability etc. are all associated with unaddressed hearing loss (Freeburg, 1991) (Furlonger, 1998) (Gilani, 2017) (Hall, 2018). Research suggests uncorrected hearing loss impedes learning (Pittman, 2011) and youth with deafness or hard of hearing (DHH) face significant barriers while transitioning from school to community, primarily due to communication problems with the general public and difficulties obtaining employment. This often leads to broader problems such as difficulty in forming adult identity, low self-esteem, social isolation and lack of assertiveness.

#### *Lower rate of education, employment or training*

Youth with any kind of disability, including DHH, also have fewer qualifications and are twice as likely to be unemployed or underemployed. When they do manage to find gainful employment, they earn less than their peers without disability. NZ's Labour Market Statistics (Disability) June 2019 quarter shows 43% of disabled youth aged 15–24 years were not in employment, education, or training (NEET). This was more than four times the NEET rate of non-disabled 15–24-year-olds. The labour force participation rate for people aged 15–24 years with a disability was 31%, well below that of non-disabled people in the same age group (61%). The 2018 Statistics NZ figures showed 41% of disabled youth had no qualification, compared with 19% of non-disabled youth.



### *Global economic impact*

The World Health Organization report titled “Global costs of unaddressed hearing loss and cost effectiveness of interventions” puts the annual cost of unaddressed hearing loss in the range \$750–790 billion USD globally, primarily towards education, healthcare, loss of productivity and the societal cost resulting from social isolation, communication difficulties and stigma attached to hearing disabilities (World Health Organisation, 2019).

The costs are calculated on the basis of the monetary value attached to avoidance of a year lived with disability and draw upon disability-adjusted life years (DALYs) attributed to hearing loss. However, it takes no account of certain aspects of hearing loss such as the costs of providing informal care, or preschool learning and higher education for people with unaddressed hearing loss. Such costs are not well documented in the literature.

## Study Background

The Principal researcher for this study will be Natasha Gallardo, the CEO of the National Foundation for the Deaf and Hard of Hearing.

Secondary schools (M/F) will be selected to provide a representative sample of the demographic diversity of New Zealand, and each year, a cohort of year 9 students will be tested. The purpose of this is to identify trends in hearing loss in the population. At each school, all students of the appropriate year group will be included as potential participants.

### *Expected benefits and merit of the research, and how they outweigh the harms*

The majority of adolescents and youth globally now have access to personal hearing devices including smart phones and iPods that they use to listen to music, using headphones and earbuds, often at high volumes for extended periods. This, combined with regular attendance at music and other noisy recreational events, is contributing to what is now seen as a global trend of increase in non-occupational noise-induced hearing loss. The World Health Organisation (WHO) estimates at least one billion people aged between 12-35 years are at risk of hearing loss due to such preventable recreational risk factors.

To determine whether the global trend was following a similar path in New Zealand, the National Foundation for Deaf and Hard of Hearing (NFDHH) embarked on a pilot programme in 2019 of auditory screening of Year 9 high school pupils at secondary schools throughout New Zealand. Data collected since the commencement of this programme suggest that student are listening to music every day on personal devices for extended periods, and a number of students’ above what the World Health Organisation’s Safe Listening Standards prescribe for maintaining hearing health. The proposed approach minimises the risk of harm for participants as a result of the study.

### *Summary of the proposed research*

Secondary schools across New Zealand, representative of the diversity in New Zealand’s population, will be selected. The Foundation will approach the school’s Deputy Principal and/or Nurse, and acquire consent of parents/guardians prior to study commencement through the schools’ consent process. Based on the number of participants per school, the NFDHH staff members will conduct hearing screening checks according to the B4 school hearing screening programme. We will screen current year 9 students each year.

The audiometric screening will include a series of tones between 500 and 4000 Hertz (Hz) at 20 to 40 Decibels (dB). Prior to each instance of screening, the hearing screening questionnaire is filled out by the student.

In case the study uncovers previously unknown hearing loss, results may be shared with the school so long as the parent/guardian has given consent, and the parents/guardians will then be informed via the Deputy Principal and/or Nurse. Researchers will refrain from giving an opinion about how the hearing loss should be dealt with by a health professional, so as not to interfere with the health professional-patient relationship. If prior consent is given by parents/guardians, the Foundation will seek information of the outcomes of the full assessment for research purposes.

### *Hypotheses or objectives*

The objective of this study is to follow the trends in noise-induced audiometry threshold shifts over a period of time and identify potential future risk of non-occupational NIHL among students in year 9 in New Zealand.



### *Main outcome(s) of interest*

- Extent of and trends in hearing loss in adolescent populations in NZ
- Risk between hearing loss with personal device usage

## Risk Management

### *Description of the ethical and regulatory aspects, including the ethical risks and considerations raised by the study, and how researchers propose to deal with them*

There are not considered to be significant ethical risks relevant to this study. Burdens and benefits are equitably distributed through selecting demographically representative schools. Parents/guardians of students with previously unidentified hearing loss will be informed and enabled to seek advice from medical professionals. This study does not provide any clinical medical advice to participants, however it does provide an optional referral letter for a free diagnostic test (covered by the District Health Board or Triton Hearing Clinic) to be used by the parents/guardian should they decide to follow up on an impaired hearing result. There is also funding available for hearing aids, should these be required.

We acknowledge that detection of hearing loss may cause concern, and we provide support if required. Participants may, at any point, terminate their participation in the study and they will be made aware that if they have any concerns or questions, they can talk to us, their school or their parents/ guardians.

We will work with schools to ensure that we and our researchers take a culturally appropriate approach which considers the needs and experiences of the range of ethnicities involved.

### *Description of consultation undertaken, and how researchers have incorporated feedback into the research design*

The hearing screening provided by the Foundation will follow the processes and procedures of the Foundation.

### *Partnership arrangements in place with whānau, hapū and iwi*

As schools will be selected to be representative of New Zealand's demographic, partnerships with iwi are not relevant to this study.

### *Detailed description of, and clear justification for, the study design:*

The audiometric screening given to the cohorts of year 9 students is a standard hearing test as used by the Foundation. The frequencies, order of frequencies and loudness used in this screening will not vary, in order to enable comparative data analysis.

Prior to each screening event, students are asked to fill out the pre-screening questionnaire in a quiet room at the screening venue within the school premises, as designated by the school administration, under supervision by the screening technician. The questionnaire includes questions on demographics (including age, gender, ethnicity), family history of hearing impairment, medical history (ear, nose, throat infections), and lifestyle factors (including regularly listening to music on high volume for long hours, living near a noisy environment etc.).

The inner structure of the ears will be examined (non-invasive) using an otoscope, to examine the ear canal for any obstruction (e.g. wax) and the condition of the eardrum, which can indicate inflammation, scarring or middle ear infections. HearX digital screening tool will play a series of tones through headphones in each ear, separately. The screening consists of the following steps, as described in the B4 school hearing programme from the Ministry of Health:

1. A tone of 1000 Hz at 40 dB in the right ear
2. A tone of 1000, 2000 and 4000 Hz at 20 dB in the right ear
3. A tone of 500 Hz at 30 dB in the right ear
4. A tone of 1000 Hz at 40 dB in the left ear
5. A tone of 1000, 2000 and 4000 Hz at 20 dB in the left ear
6. A tone of 500 Hz at 30 dB in the left ear

### *Criteria for including or excluding potential participants, with justifications*

Any student of participating schools in year 9, with individual consent as well as consent from parents/guardians, will be included in the study, with the exception of those who had an acute illness in the six weeks prior to the screening, and those who have previously been diagnosed hearing loss of any degree.

### *Criteria for terminating the study, if appropriate*

The study will be terminated if funding is not available.



### *Actual or potential conflicts of interest, and how researchers will manage them*

The study design and objectives do not give rise to any conflicts of interest.

## Data Management

### *What data will be collected, stored and used, and how it will be collected, stored, used and kept private*

Prior to each screening event, students will fill out an online pre-screening questionnaire, via a URL on the NFDHH hearing hub website. This area is secured through a log-in that only the Foundation staff have access to. Collected data will be downloaded and stored in a secure cloud server by the Foundation that only the Chief Executive has access to. This data will be stored for a maximum of 10 years. Collected data includes demographics (including age, gender, ethnicity), family history of hearing impairment, medical history (ear, nose, throat infections), and lifestyle factors (including regularly listening to music on high volume for long hours, living near a noisy environment etc.). During the HearX screening, a screening report is also collected and saved in a cloud server (located in Australia) by the Foundation that is accessible only by the Chief Executive. The HearX report contain identifiable data (name) and will be assessed and analysed for trends, and then the underlying data will be deleted.

Results of the questionnaires and the HearX screening will not be shared with anyone beyond the researchers (the Foundation), the participant, their parents/ guardians (if they opt-in to receiving results) and anyone they or their parents/ guardians authorise. If the parents/ guardians give their consent, the child's school will receive the test results if hearing loss is detected, so they can provide the appropriate support. However, parents may choose to receive the results directly instead. Screening results will be made available to healthcare professionals should they be involved, with parent/ guardian consent. Children and parents/ guardians have the right to access their own data at any point.

The Foundation will securely hold all information for a period of 10 years as described in their privacy policy. Participants and parents/guardians are able to access the data stored about them at any time.

### *Number of participants required to achieve the study objectives, and how the researchers determined this, for example using statistical methods*

This study is designed to enable comparative data analysis in order to observe trends and correlations as stated under the study objectives. Because of the observational and potentially beneficial nature of the study to participants, we assume the majority of students in year 9 who are eligible to participate. As a result of this, there is no specific number of participants, nor is the study design sensitive to incomplete data sets.

### *Analysis plan appropriate to the study design*

To perform comparative data analysis, standard statistical methods will be used. These are likely to include:

- Trend analysis, including regression analysis using Excel or R, to identify correlations between listening behaviours and hearing loss over a five-year period
- Analysis to identify any correlations between relevant demographic factors and hearing loss

### *How the study results will be shared publicly and communicated to participants*

Individuals' screening results will be communicated to students and their parents/guardians as per the study design. A collective report of the aggregated data will be publically published through the NFDHH's website. This report will not include any identifiable information and/or disclose the study participants.

### *Disposal of study data*

Data will be retained by NFDHH as per our privacy policy. This includes holding all research information securely for a period of 10 years for auditing purposes.





## References

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## NATIONAL FOUNDATION FOR Deaf & Hard of Hearing

### **POLICY 28: PRIVACY POLICY – YOUTH PROGRAMME**

The National Foundation for The Deaf Incorporated (**we, us or our**) operates a Youth Programme where we carry out free hearing screenings for students who participate in the programme (**students**) at selected secondary schools in New Zealand (**Programme**). Our partner Proactive carries out the hearing screenings at school premises.

This privacy policy sets out details of how we collect, use, store and disclose the personal information of students. By consenting, as the parent or guardian of a student, to the participation of your son or daughter in the Programme, you consent to the collection, use, storage and disclosure of the personal information of your son or daughter in accordance with this policy.

If you choose not to allow your son or daughter to participate in the Programme, no personal information relating to your son or daughter will be collected.

#### **HOW WE COLLECT STUDENTS' INFORMATION**

We will only collect personal information that is relevant to students' participation in the Programme. The personal information we collect will generally include the student's name, class, and the results obtained from his or her hearing screening. We will collect this information directly from the student when he or she completes a Programme questionnaire and participates in the Programme.

#### **HOW WE USE STUDENTS' INFORMATION**

We will only use students' personal information for the operation and purposes of the Programme. We may disclose the personal information that we collect to:

- our partner Proactive;
- you, or any other family member, guardian, or other person that you authorise us to disclose the personal information to; or
- any relevant members of the school's staff, including the student's teachers, the principal or a deputy principal, or medical staff such as a school nurse.

We will not otherwise disclose the personal information of students to any other person. However, while it is unlikely, we may be required to disclose students' information to comply with legal or regulatory requirements. We will use reasonable endeavours to notify you before we do this, unless we are legally restricted from doing so.

We may use, disclose or transfer to third parties any non-personal, aggregated information that is collected from students and others. This includes, for example, information regarding hearing trends.

#### **SECURITY OF INFORMATION**

Only our staff and those who perform services on our behalf, and are authorised to handle the information, will have access to students' personal information. Students' personal information will be kept secure and confidential, using up to date measures which meet current industry standards. The personal information will be stored on servers located in Australia. It will not be retained for longer than is required except to fulfil our legal obligations or where you have consented to such retention.

## **ACCESS TO INFORMATION**

You can access the personal information that we hold about your son or daughter and request corrections. This right is subject to some exceptions, for example you may not obtain access to information relating to existing or anticipated legal proceedings. You can request access to this information by emailing us at [enquiries@nfdh.org.nz](mailto:enquiries@nfdh.org.nz) or by writing to us at -Level 1, 149-155 Parnell Road, Parnell, Auckland 1052 or PO Box 37729, Parnell, Auckland 1052.

## **COMPLIANCE AND CHANGES TO POLICY**

As well as complying with this policy, we will comply with our general privacy policy at <https://www.nfdhh.org.nz> in relation to the collection, use, storage and disclosure of the personal information of students.

We may change this policy at any time by sending you the amended policy or publishing the amended policy on our website. We will endeavour to inform you of any changes to the policy by email or on the website. If you have any questions about this policy or any changes to it, you can contact us by email at [enquiries@nfdhh.org.nz](mailto:enquiries@nfdhh.org.nz) or by writing to us at - Level 1, 149-155 Parnell Road, Parnell, Auckland 1052 or PO Box 37729, Parnell, Auckland 1052.

## **ENQUIRIES**

If you wish to enquire or complain about the way that we have managed your son's or daughter's personal information, please contact us at [enquiries@nfdhh.org.nz](mailto:enquiries@nfdhh.org.nz) or write to us at Level 1, 149-155 Parnell Road, Parnell, Auckland 1052 or PO Box 37729, Parnell, Auckland 1052. We will endeavour to respond promptly to your enquiry or complaint.