



Information letter from the Hearing Register for Children

Background

The Hearing Register for Children registers children who do not pass the newborn hearing screening, or children aged 0–18 years who are diagnosed with permanent hearing loss. Permanent hearing loss can have major consequences for children, and unless adaptive measures are put in place, such children will be at risk of falling behind their peers with normal hearing in terms of language and communication, cognitive functioning, reading and writing skills, and socioemotional development. The collection and evaluation of data will increase our knowledge about what affects hearing, and linguistic and psychosocial functioning in children with a hearing loss.

Purpose

The purpose of the register is to quality assure appropriate and safe treatment for the whole patient group, and to improve our knowledge of the treatment in relation to both individual patients and the patient group as a whole. The Register can help to ensure that better, more uniform treatment is offered, increase interest and research within the field, and ensure that the general population is better informed.

What information will be registered?

The following information will be registered: year of birth, place of residence, diagnosis, assessment and treatment, diagnosed problems other than hearing loss, and parent-reported information about the child.

See the website <https://horselsregisteret.no> for a more detailed description of the Register.

Where will the information be obtained from?

Information about children will be collected by medical personnel in connection with referrals and appointments at the ENT Department, when the newborn hearing screening is not passed, when a permanent hearing loss is diagnosed, and at subsequent check-ups at the age of 3, 6, 10 and 15 years. Questionnaires will be sent electronically to the parents of children with permanent hearing loss in advance of relevant check-ups to collect information about the children.

Right of access, right to rectify information, and right to opt out

Pursuant to Sections 24-25 ff. of the Personal Health Data Filing System Act, you may at any time request access to information registered about your child, or demand that the information be rectified or erased. You have a right to refuse consent for the storage and further use of personal and health data about the child in the Hearing Register for Children. If you do not wish information about your child to be stored, you may, at any time and without stating a reason, opt out of registration. It will have no bearing on the child's treatment if you choose to opt out, or if you wish to withdraw at a later date. In such case, information about the child will be erased from the Register. However, as the data controller, St. Olavs Hospital will continue to process the information insofar as this is necessary for it to fulfil its duty to ensure that persons who have opted out of registration are not subsequently re-registered. Erasure of data does not entail erasing anonymised research files that have already been used in research.

You can opt out of registration of the child by logging on to www.helsenorge.no, by giving notification of this in connection with appointments at the ENT Department or by contacting the Hearing Register for Children. You will find a guide to the right of access to information, erasure and restriction of information at <https://tjenester.helsenorge.no/helseregistre> and on the website <https://horselsregisteret.no>.

You can contact the Norwegian Data Protection Authority or the Norwegian Board of Health Supervision if you believe that health data are not being processed in accordance with the Regulations relating to medical quality registries or other relevant regulations.



Norsk Kvalitetsregister Øre-Nese-Hals, Hørselsregisteret for barn

Laws and regulations

The Hearing Register for Children is regulated by the Regulations concerning medical quality registries, the Personal Health Data Filing System Act and the General Data Protection Regulation. The Register will be used to carry out tasks that are in the public interest, and its legal basis is the General Data Protection Regulation Article 6 (1) letter e) and Article 9 (2) letters g), h), i) and j). The Personal Health Data Filing System Act and the Regulations concerning medical quality registries supplement this legal basis in domestic law. Information about the child's contact with the specialist health service may be collected and used by the Register without consent, but you have a right to information and to opt out the Register's processing of information about your child. The data in the Register will be stored for as long as the Register has a lawful basis for doing so pursuant to the General Data Protection Regulation Article 6 (1) letter e) and the Regulations concerning medical quality registries, and for as long as it is relevant and necessary for the purposes for which they are processed.

Data are registered electronically and are protected against unauthorised access. All information will be processed with respect for data protection and privacy and in compliance with applicable laws and regulations.

Processing of data in the Register

The data in the Register are stored in de-identified form, meaning that the date of birth and national ID suffix are replaced by a code. All persons who have access to the data in the Register are subject to a duty of confidentiality. Your personal data may only be disclosed, or otherwise made available, in accordance with laws and regulations, including rules relating to the duty of confidentiality and the European General Data Protection Regulation (GDPR). Information from the Register can be used in the management of the health service, to improve the quality of treatment and for research purposes.

It will be possible to retrieve information from patient records to clarify details about the diagnosis and the treatment given. It will also be possible for the Register to retrieve and collate relevant additional information from other national medical quality registers and health registers established pursuant to the Personal Health Data Filing System Act Sections 8 to 11, using information in the National Population Register and socioeconomic data from other public registers. Examples of relevant public registers and population surveys: the Norwegian Patient Register, the Medical Birth Register of Norway, the Norwegian Neonatal Network, the Norwegian Prescription Database, the Cancer Register of Norway, the Cause of Death Register of Norway, Statistics Norway's registers, the FD-Trygd Database, the Norwegian Labour and Welfare Administration (NAV), the Directorate of Taxes' databases, population surveys that are part of Conor, relevant ENT sub-registers, the national health surveys programme, the Tromsø Study, HUNT and KUHR (control and payment of reimbursements to health service providers). Data will regularly be linked to the Norwegian Patient Register in order to measure the coverage and validity of the Hearing Register for Children.

Collaboration has been established with other Nordic hearing registers for children. There are plans to regularly compare anonymised data sets, and to initiate international research based on the different registers. You may also be invited to participate in special research projects relating to the purpose of the Register.

All collating of data requires prior approval from publicly approved bodies. It will not be possible to identify individuals from results based on analyses from the Register.

Annual national reports will be prepared by the Register, and data will be made available to the general public on the websites mentioned below. Results will also be published on a continuous basis at professional conferences and in national and international medical journals.

More information about the Register: www.kvalitetsregistre.no and <https://horselsregisteret.no>

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