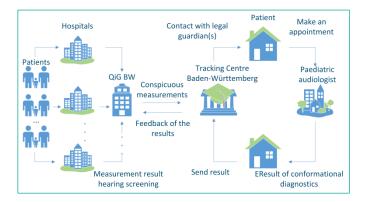
Tracking for the newborn hearing screening

What happens to the data?

The maternity clinic transmits the data described above in encrypted form to the Quality Assurance Department in Gesundheitswesen Baden-Württemberg GmbH (QiG BW GmbH) in Stuttgart. Only if the examination results of your child transmitted by the maternity clinic need to be checked will the data described above be transmitted in encrypted form by QiG BW GmbH to the tracking centre for newborn hearing screening in Heidelberg.

The personal data of the mother and the child transmitted by QiG BW GmbH are used exclusively for contacting you (by letters, telephone calls) within the framework of the tracking procedure. The above-mentioned personal data will not be used or evaluated for any purposes other than those mentioned and will not be disclosed to unauthorised third parties.

Only authorized employees of QiG BW GmbH and the tracking centre in Heidelberg have access to this personal data. The employees are, of course, subject to the duty of confidentiality. After completion of the tracking, the results of the confirmatory diagnosis (confirmatory examination) of the child are returned to QiG BW GmbH in encrypted form. See the graphic below:



The personally-identifying data of the mother and the child will be deleted 12 months after the end of the tracking in the tracking centre in Heidelberg. The deletion of the pseudonymized data in the QiG BW GmbH as well as the tracking centre in Heidelberg takes place 10 years after completion of the tracking. At any time you have the right to request information from the persons responsible about the stored personal data of your child (see below). You may also request the correction of inaccurate data and the deletion of data or the restriction of their processing. Participation is voluntary and the cost is borne by the statutory health insurance funds and the state of Baden-Württemberg. This means for you that the tracking as well as the hearing screening is free of charge.

We therefore recommend that you use this free service to give your child a good start in life.

Newborn hearing screening Tracking Centre Baden-Württemberg Dietmar Hopp Metabolism Centre

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UniversitätsKlinikum Heidelberg: Tracking Neugeborenenhörscreening

Further information on data collection and processing within QiG BW GmbH can be found at: <u>www.qigbw.de</u> E-mail: datenschutz@qigbw.de



Baden-Württemberg

Information Leaflet for Parents TRACKING NEWBORN HEARING SCREENING





English

Tracking newborn Hearing screening is supported by The Ministry of Social Affairs and Integration from funds of the State Baden-Württemberg



Dear Parents,

the birth of your child is still ahead or just behind you. We wish you all the best for your child.

Why is hearing screening useful?

Out of 1000 children, 2-3 are born with a hearing disorder requiring treatment. A hearing loss that is not diagnosed early can have a negative effect on the entire development: In addition to a disturbed speech development, psychosocial and intellectual development can be impaired. Especially the first months of life are crucial for hearing. The longer the hearing loss remains undetected, the more difficult it becomes for the child to catch up in speech development. If the hearing impairment is detected very early, modern hearing-aid technology and early support can make it much easier for the child to start in the life.

How is the newborn hearing screening performed?

The hearing ability of a newborn can be tested using two measurement methods:

Otoacoustic Emissions (OAE)

During the measurement, an earplug with a small probe is inserted carefully into the outer ear canal. This emits a quiet "click" sound, to which the sensory cells in the inner ear react with vibrations that can be measured as a response noise with a microphone on the probe. If this answer is available, the middle ear and cochlea will work.

Automated Brain Stem Audiometry (AABR)

This examination measures the reactions of the brain to a probe tone. Small electrodes are attached to the forehead, neck and cheekbones or the measurement is carried out via the electrodes integrated in the screening device. As with the OAE measurement, quiet "click" sounds are sent to the ear. The electrodes measure whether the sound waves are transmitted and processed as electrical impulses to the brain. If this reaction is measurable, the middle ear, cochlea, auditory nerve and lower part of the auditory pathway are functioning.

Is the examination stressful?

During the hearing screening one of these two measurement methods will be used for your child. The examination is easiest to perform when the baby has drunk and is asleep. It lasts a few minutes and is completely painless and in no way stressful for your baby.

What does the test result in hearing screening mean?

An inconspicuous result means that a hearing disorder is largely excluded. However, a hearing disorder can occur in the course of a child's development, for example through repeated middle ear infections in infancy. Therefore, even after an inconspicuous test result, it is important that you as parents continue to pay attention to whether your child hears well.

A conspicuous result or a result that needs a follow-up first requires a repeated measurement on the same day or on the next day in your maternity clinic.

Very few of the children screened as conspicuous/ in need of a follow-up really have a hearing disorder. On the one hand this is due to the evaluation method, which under no circumstances wants to overlook a child in need of treatment and therefore accepts the follow-up examination of ultimately hearing children, and to "obstacles" in the newborn examination on the other (e.g. vernix caseosa in the auditory canal or amniotic fluid in the middle ear). Only about 1 child from 30 to 40 children with a conspicuous result in screening actually has a hearing disorder.

In the case of a repeated conspicuous result, however, we strongly recommend a confirmatory examination by a specialist within four weeks. He or she will carry out further examinations to give you certainty about your child's hearing and can immediately initiate any treatment that may be necessary.

Can hearing disorders in newborns be treated?

If a newborn hearing disorder is detected during further examinations, it cannot be cured in most cases, but can be treated effectively. The earlier the treatments, the more effective they are. For this purpose, the tracking centre contacts the parents to clarify the status of the examinations. Tracking continues until a final result is obtained.

Tracking is voluntary and complements the hearing screening examination that has been carried out since 2009. For the transmission of personal data to QiG BW GmbH for quality assurance measures and tracking the consent of at least one legal guardian (e.g. mother or father) is mandatory.

This allows the treatment of a possible hearing disorder to be started at an early stage.

Data collection and processing

In order to perform tracking in newborn hearing screening, the information on the mother's and child's personally identifying data is a basic prerequisite. Without this information and their consent to the transfer of data (or, if applicable, primary carer) tracking is not possible (pursuant to art. 6 para. 1 let. of the GDPR).

What data is collected?

The main focus is on the results of the newborn hearing screening examination (left ear: positive/negative; right ear: positive/negative) of your child and the personally-identifying data of the mother (surname, first name, address, telephone) and your child (surname, first name, date of birth). Should the primary carer be other than the mother, the data of this person (surname, first name, address, telephone) are also collected. The entire dataset can be viewed on the homepage of the service centre (www.qigbw.de) under State Procedures ► QS UNHS BW, for example in the document on the instructions.

Tracking for the newborn hearing screening

The tracking of conspicuous measurement results ensures that a confirmation diagnosis is made by the paediatric audiologist in good time.