

## **Parent information for the collection and processing of personal data for the newborn hearing screening**

### **Dear parents,**

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

Every newborn child in Germany is legally entitled to a hearing screening examination. In Baden-Württemberg, the newborn hearing screening is supported by the Neugeborenen-Hörscreeningzentrale Baden-Württemberg [Baden-Württemberg Newborn Hearing Screening Centre]. The Newborn Hearing Screening Centre is funded by the Ministry of Social Affairs, Health and Integration from federal state funds approved by the Baden-Württemberg state parliament.

The data on the newborn hearing screening is transmitted from all maternity clinics in Baden-Württemberg to the Newborn Hearing Screening Centre. The prerequisite for the transfer of the data is the **voluntary** consent of both legal guardians (mother and father). The data is analysed anonymously for quality assurance purposes with the aim of ensuring that the examination is carried out properly and in accordance with legal requirements. Furthermore, in the event of abnormal or missing results, follow-up will be performed by contacting parents or legal guardians. The objective is to optimise prompt clarification and early commencement of therapy (if a hearing disorder is detected).

The Baden-Württemberg Newborn Hearing Screening Centre consists of QiG BW GmbH, which processes the data from the maternity clinics for quality assurance purposes, and the Tracking Centre for Newborn Hearing Screening in Baden-Württemberg at the Dietmar Hopp Metabolic Centre at Heidelberg University Hospital, which carries out the associated follow-up of abnormal and missing examinations by contacting the parents (= tracking). The Tracking Centre transmits the results of tracking, including information provided by practices, to QiG BW in pseudonymised form for quality assurance purposes.

If the result of your child's **hearing screening examination** at the hospital is **normal**, the data will be pseudonymised, encrypted and sent to QiG BW for analysis, provided that you have given your consent. 'Pseudonymised' means that data that could be used to identify subjects is replaced by a pseudonym – in this case with a number ('processing number'). The aim of pseudonymisation is to ensure that the identity of the person concerned can only be determined by a group of specially authorised persons in the maternity clinic.

If the **screening** of your child was **abnormal** or the newborn hearing screening was not carried out on one side, the criteria for tracking (follow-up of abnormal and missing findings by contacting the parents/guardians) are fulfilled. In order to carry out the tracking, the contact details of a legal guardian (usually the mother or father) are required. If you have given your consent, these are added, encrypted and sent to QiG BW, which cannot view them and will pass them on to the Tracking Centre. Tracking is free and voluntary. For further information on tracking and the associated data processing, please refer to the information documents of the Tracking Centre.

The strictest data protection and data security measures are required for data transmission and processing. The data is encrypted in a highly secure manner and transmitted via precisely defined transmission paths. The entities involved in data collection and processing fulfil all data protection requirements. The data will neither be transferred to external third parties, nor to a country outside the EU or EEA or to an international organisation.

### **Information on data processing in accordance with Art. 13 and 14 of the EU GDPR:**

#### **Authorities responsible for data processing:**

- QiG BW GmbH (Qualitätssicherung im Gesundheitswesen Baden-Württemberg), Birkenwaldstr. 145, 70191 Stuttgart, phone: 0711/184278-00, e-mail: [info@qigbw.de](mailto:info@qigbw.de)

- Tracking Centre for Newborn Hearing Screening in Baden-Württemberg, Dietmar Hopp Metabolic Centre Heidelberg, Im Neuenheimer Feld 669, 69120 Heidelberg, phone: 06221/56-6315, e-mail: [neugeborenen.hoerscreening@med.uni-heidelberg.de](mailto:neugeborenen.hoerscreening@med.uni-heidelberg.de)

#### **Legal basis for the processing:**

Art. 6 para. 1(a) GDPR in conjunction with. Art. 9 para. 2(a) GDPR in conjunction with your consent.

**Contact details of the data protection officer:**

- Tracking Centre for Newborn Hearing Screening in Baden-Württemberg, Data Protection Officer of Heidelberg University Hospital, Im Neuenheimer Feld 672, 69120 Heidelberg, e-mail: [datenschutz@med.uni-heidelberg.de](mailto:datenschutz@med.uni-heidelberg.de)
- QiG BW GmbH, Data Protection Officer, Birkenwaldstr. 145, 70191 Stuttgart, e-mail: [datenschutz@qigbw.de](mailto:datenschutz@qigbw.de)

**Purposes of data processing:**

- Quality assurance in accordance with legal requirements and - if the criteria for tracking are met - for contacting parents or legal guardians
- Evaluations of the quality of treatment for data-providing maternity clinics, which are used for targeted quality improvement and thus benefit future newborns and their parents. Each maternity clinic can consult its own password-protected results and compare them with the anonymised results of other maternity clinics in Baden-Württemberg. The evaluations do not contain any personal data but merely present the calculated results.
- Evaluations for Baden-Württemberg, which are published on the QiG BW homepage. These also do not contain any personal data.

**Categories of processed personal data:**

- Information on the hearing screening examination and on the health status of your child as well as other relevant information concerning the hospital stay
- Processing number for pseudonymisation of the data
- Contact details of the mother or a legal guardian (if your child's newborn hearing screening was abnormal or was not performed on both sides)

**Storage period:**

At QiG BW, the data deliveries received and the e-mails for data transmission are deleted in April of the year following receipt. After three years, the data records are anonymised by deleting the processing numbers from the database. The case-related data will be deleted after 10 years. The encrypted contact details, which cannot be viewed by QiG BW, are forwarded to the Tracking Centre. Because of the need for a temporary storage by QiG BW, they are overwritten with meaningless content, so that the content can no longer be read. The encrypted contact details will be completely deleted in April of the year following their receipt.

In the Tracking Centre, the contact details and contents of the text fields, data deliveries received from QiG BW and e-mails regarding data transmission are deleted after tracking is completed in the following year. Pseudonymised case-related data (track ID, tracking data records) is deleted 10 years after completion of tracking.

**Your rights:**

You have the right to request information from the entities involved in data collection and processing about the processed personal data, as well as the right to request correction, deletion and restriction of processing, as well as the right to data portability and the right to object to data processing. You can reject the offer or revoke it at any time with effect for the future. The legality of data processing that has already taken place remains unaffected by revocation.

Please, address any revocation to:

-the maternity clinic where your child was born, or

-the Tracking Centre for Newborn Hearing Screening in Baden-Württemberg, Dietmar Hopp Metabolic Centre Heidelberg, Im Neuenheimer Feld 669, 69120 Heidelberg, phone: 06221/56-6315, e-mail: [neugeborenen.hoerscreening@med.uni-heidelberg.de](mailto:neugeborenen.hoerscreening@med.uni-heidelberg.de).

You also have the right to lodge a complaint with the competent supervisory authority:

The State Commissioner for Data Protection and Freedom of Information Baden-Württemberg  
Lautenschlagerstraße 20, 70173 Stuttgart, phone: 0711/615541-0, e-mail: [poststelle@lfdi.bwl.de](mailto:poststelle@lfdi.bwl.de).

*In case the hearing screening could not be completed during the hospital stay,  
you can find a suitable doctor's office on the following list:*  
[www.qigbw.de/neugeborenen-hoerscreening-baden-wuerttemberg](http://www.qigbw.de/neugeborenen-hoerscreening-baden-wuerttemberg)



**Declaration of consent to the processing of personal data for the newborn hearing screening**

I/we have been informed about the data collection and processing in the context of the quality assurance procedure for newborn hearing screening and the possible tracking procedure (see parent information on data collection and processing).

Surname and first name of the child/children: \_\_\_\_\_

Date of birth of the child/children: \_\_\_\_\_  
(or adhesive label)

My/our consent\* includes the processing of

- ✓ my data (mother) and
- ✓ the data of our child/children for the newborn hearing screening and
- ✓ our contact details for the tracking

by the maternity clinic, QiG BW GmbH and the Tracking Centre for the purposes of quality assurance and tracking in the event of missing or abnormal findings.

**I/we\* consent to the data processing for the newborn hearing screening and the tracking, the transfer of the data collected for this purpose to QiG BW GmbH and the Tracking Centre and contact by the Tracking Centre:**

☐ Yes ☐ No

**Consent is voluntary and can be refused or revoked at any time without giving reasons. If only one parent signs the consent form, the signatory assures that the other parent has consented to the data processing (e.g. verbally).**

\_\_\_\_\_  
Surname, first name of the mother in capital letters

\_\_\_\_\_  
Place, date

\_\_\_\_\_  
Signature of the mother

\_\_\_\_\_  
Place, date

\_\_\_\_\_  
Signature of the father

**\*If both parents are not the legal guardians, then it is necessary to document not only the mother's consent to the processing of her data, but also the consent of the legal guardian for the processing of the data of the child/children:**

\_\_\_\_\_  
Surname, first name of the legal guardian in capital letters

\_\_\_\_\_  
Place, date

\_\_\_\_\_  
Signature of the legal guardian

*(Note to documentation staff in the hospital: Please enter the contact details of the legal guardian in the appropriate fields in the quality assurance form, if necessary.)*

You can find all the information on newborn hearing screening (information on data processing, tracking...) at:  
<https://www.qigbw.de/neugeborenen-hoerscreening-baden-wuerttemberg>

