



Information for parents

Registration in **NEORAH**

You are receiving this information because your child's heel prick test result is abnormal. Your child has been referred to a paediatrician for follow-up diagnostic testing. Your child's details will be registered in the information system NEORAH. These details include your child's personal data, the abnormal heel prick test result(s) and the result of follow-up diagnostic testing. NEORAH is short for Neonatal Register for Abnormal Heel Prick Test Results.

Why is it important to register your child's details in NEORAH?

The registration of details in NEORAH serves a number of different purposes.

RIVM uses NEORAH to keep a record of abnormal heel prick test results. A paediatrician in a hospital will consult the child's record to carry out follow-up diagnostic testing. He or she will then update NEORAH with the results and the conclusion of follow-up diagnostic testing. That way, RIVM will know whether the child has the disease for which it has been referred. This is essential information, as it allows RIVM to assess whether the heel prick test works or needs to be improved.

RIVM also uses the details in NEORAH to assess whether the conversion of a heel prick test result into a hospital referral is accurate and quick.

Moreover, specialist paediatricians can use the details in NEORAH for scientific research to improve hospital care.

To sum up, the details in NEORAH are used to assess whether the heel prick test can be improved and to improve the care for children with particular diseases.

Some test results are included in the annual heel prick test monitoring report. This annual monitoring report does not include personal data that can be directly traced back to your child, such as its name, date of birth or citizen service number. This guarantees that the privacy of children is respected.

Registration of details in NEORAH

To safeguard the quality of the heel prick test, it is vital that the details of all children that we refer to a paediatrician are registered in NEORAH.

Should you wish to opt out of this, then RIVM can uncouple the heel prick test results and the results and the conclusion of follow-up diagnostic testing from your child's personal data, such as its name, date of birth and citizen service number. This way, the outcomes and results can still be used, but they can no longer be traced back to your child. After this uncoupling, RIVM can remove the aforementioned personal data from NEORAH. If you would like us to do so, please contact the RIVM-DVP office in your local area (see the next page under 'Contact details').

Privacy

RIVM acts as the data controller with respect to NEORAH. NEORAH is well secured and the laws that protect your child's privacy apply to NEORAH as well. The details can only be accessed by people who need them for the purpose of treating your child or to conduct research, such as paediatricians.

The details in NEORAH are retained for a period of 20 years.

Do you have a question or complaint about NEORAH?

If you have a question or complaint about the registration of details in NEORAH, please contact the RIVM-DVP office (see below). Alternatively, you can contact RIVM's Data Protection Officer at FG-VWS@minvws.nl.

Lastly, you can file a complaint with the Dutch Data Protection Authority at www.autoriteitpersoonsgegevens.nl/en.

More information

If you would like more information (in Dutch) about the registration of details in NEORAH, go to the 'Details and privacy' web page at www.pns.nl/hielprik/gegevens-en-privacy.

Nederlandse tekst

De Nederlandse versie van deze informatiebrief vind je op www.pns.nl/documenten/registratie-in-neorah.

Contact details of RIVM-DVP offices

- RIVM-DVP West (Utrecht, North Holland and South Holland), dvpwest.nhs@rivm.nl, 088 689 8931
- RIVM-DVP South (Limburg, North Brabant, Zeeland), dvpzuid@rivm.nl, 088 689 8941
- RIVM-DVP North East (Drenthe, Flevoland, Friesland, Gelderland, Groningen, Overijssel), dvpnoordoost@rivm.nl, 088 689 8951

The logo for NEORAH, featuring the word "neorah" in a lowercase, teal-colored sans-serif font. The letter "o" is replaced by a white footprint icon.

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