

Dear parent or guardian,

Your child regularly attend the HIV outpatient clinic for check-ups relating to his/her HIV infection. To give your child the best possible treatment, the HIV treating physician and/or HIV nursing consultant collect personal and medical data in the medical file of your child. With your explicit consent, the data of your child may also be used by stichting hiv monitoring (SHM) for scientific research. This letter contains brief information about the collection of your child's personal data.

Extensive and current¹ information can be found on our website:

www.hiv-monitoring.nl

Why your child's data are collected

On behalf of the RIVM infectious disease control center (Cib) SHM will use the data of your child for the purpose of national HIV monitoring and for scientific research. SHM works in scientific collaboration with researchers in the Netherlands, Europe and elsewhere in the world. The outcomes of this research will contribute to an improvement in HIV care in the Netherlands.

More information about our collaborative partnerships and research can be found on www.hiv-monitoring.nl

When, where and what sort of data are collected of your child and how SHM safeguards your child's privacy

Once you have given your explicit consent, SHM's data collector will collect the relevant data from your child's medical file. You can withdraw your consent, until the age of 11², at the HIV treating physician or HIV nursing consultant of your child at any time, without any consequences for your child's further treatment.

If you give your consent, the following data, for registration at SHM, will be collected:

- date of birth;
- initials (max. 2 letters);
- gender;
- nationality and country of birth; the 4 numbers of your postcode (not letters);
- date in care and out of care;
- data from an earlier registration with SHM, if you have previously attended another HIV treatment centre;
- hospital registration number; statement that written and/or oral explanation has been given.

Your child's registration data will be saved under a unique code number. Using this code number, the data collector will periodically collect medical data which

¹ Privacy law and regulations and data-collection by SHM may be subject to change. The most current information is always available on our website.

² As from the age of 12, your child is legally allowed to withdraw his or her consent without the permission of a parent or guardian.

are separately stored from your child's registration data. These are data relating to your child's medical history (including medical data of earlier HIV centres if applicable), HIV diagnosis, treatment, the progress or course of your child's infection, and any other directly or indirectly related infections and diseases. You are also giving consent to the use of relevant provisions obtained from blood samples of your child taken during the course of the treatment, including medical data from leftover blood samples material stored in the laboratory.

Use data of other registrations

In the interest of HIV monitoring and surveillance in the Netherlands your child's, not directly traceable, data can be linked with other registrations. If it is necessary to link the data within the treatment center, SHM always uses a Trusted Third Party (TTP) that, as an independent party, ensures that the data exchange complies with data protection laws and regulations.

Information about current links to other registrations can be found on our website: www.hiv-monitoring.nl.

If you do not give consent or withdraw your consent, then only basic data of your child will be registered under a unique code number for reporting the correct number of HIV infections in the Netherlands to Cib-RIVM. These data are:

- year of birth;
- gender;
- born in the Netherlands: yes/no. All other data, including the medical information, will be deleted from the SHM database after 30 days and will remain in backup files within the secure environment of Amsterdam UMC for a maximum of an additional 14 days.

In your child's medical file within the treatment centre, it will be noted that you did not give consent or that you have withdrawn your consent, and the medical data will no longer be collected. However, the treatment team will keep a list with the unique code number and hospital registration number so that SHM knows you are included in the count of HIV infections in the Netherlands that SHM must report to the Cib-RIVM. This prevents the need to repeatedly access your medical file for this purpose.

How your child's data are stored

Your child's data are stored in SHM's secure national database. Those persons who have access to this database are all bound to a professional (medical) duty of confidentiality. SHM applies very strict access and safeguarding measures. The exchange of data is always coded so the privacy of your child is optimally protected.

Who your child's data will be exchanged with

SHM only provides research institutions with data **that cannot be directly traced back to your child**. The data may not be shared with other parties and after the research has been completed they must be destroyed.

The data included in publications of research results are anonymous and cannot be traced back to you as an individual.

SHM does not provide data to commercial parties such as insurers or pharmaceutical companies.

How long will your child's data be stored

With your consent, your child's data will be stored for as long as the national HIV monitoring programme in the Netherlands is ongoing.

The medical data obtained from the material left over from your child's samples can be used for medical research for the duration of HIV monitoring in the Netherlands.

Your privacy rights

Under the privacy law General Data Protection Regulation (GDPR) you have a number of privacy rights. You can always withdraw your consent, until the age of 11, to the use of your child's medical data for the purpose of national HIV monitoring and for scientific research by telling the HIV treating physician or HIV nursing consultant of your child. SHM will stop collecting your child's (medical) data for research and anonymise the personal data.

An overview of all the rights can be found on our website:

www.hiv-monitoring.nl

Questions, complaints, more information

If you have any questions, complaints or if you want more information, you can discuss this with your child's HIV treating physician or HIV nursing consultant or you can read the extensive information on our website: www.hiv-monitoring.nl

If you have any questions about privacy, please use the contact details of the SHM Data Protection Officer below.

If you are not satisfied with the way your rights have been handled, you can always submit a complaint to the Personal Data Authority:

www.autoriteitpersoonsgegevens.nl.

Contact details SHM

Stichting hiv monitoring (SHM)

Data Protection Officer

Meibergdreef 9, 1105 AZ Amsterdam

Tel: +31205664172

E-mail: privacy.shm@amsterdamumc.nl

Website: www.hiv-monitoring.nl

Chamber of Commerce number: 34160453