

This letter is especially for you and for your parent or guardian

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

Extensive and current¹ information can be found on our website:

www.hiv-monitoring.nl.

Why your data are collected

On behalf of the RIVM infectious disease control center (Cib) SHM will use your data 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 from you and how SHM safeguards your privacy

Once you and your parent or guardian have given explicit consent, SHM's data collector will collect the relevant data from your medical file. You can withdraw your consent, without permission of your parent or guardian, at your HIV treating physician or HIV nursing consultant at any time. Your withdraw won't have any consequences for your further treatment.

If you and your parent or guardian give 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 registration data will be saved under a unique code number. Using this code number, the data collector will periodically collect medical which are separately

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.

stored from your registration data. These are data relating to your medical history (including medical data of earlier HIV centres if applicable) , your HIV diagnosis, your treatment, the progress or course of your infection, and any other directly or indirectly related infections and diseases.

You and your parent or guardian are also giving consent to the use of relevant provisions obtained from blood samples taken during the course of your treatment, including medical data from leftover blood samples material stored in the laboratory.

When you become pregnant, then the information recorded in your file on your pregnancy, the birth, and some birth data about your baby that are relevant to HIV monitoring will also be collected.

An extensive list of all the data that are collected can be found on the SHM website: www.hiv-monitoring.nl.

Use data of other registrations

In the interest of HIV monitoring and surveillance in the Netherlands your, 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 and your parent or guardian do not give consent or withdraw your consent, then only your basic data 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 your 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 medical file within the treatment centre, it will be noted that you did not give consent or that you have withdrawn your consent, and your 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 data are stored

Your 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 your privacy is optimally protected.

Who your data will be exchanged with

SHM only provides research institutions with data **that cannot be directly traced back to you as a person**. 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 data be stored?

With your consent and your parent's or guardian's consent, your 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 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, without the permission of your parent or guardian, to the use of your medical data for the purpose of national HIV monitoring and for scientific research by telling your HIV treating physician or HIV nursing consultant. SHM will then stop collecting your (medical) data for research and anonymise your personal data.

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

www.hiv-monitoring.nl

Questions, complaints, more information

If you or your parent or guardian have any questions, complaints or if you want more information, you can discuss this with your HIV treating physician or HIV nursing consultant or you can read the extensive information on our website:

www.hiv-monitoring.nl

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

If you or your parent or guardian 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

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E-mail: privacy.shm@amsterdamumc.nl

Website: www.hiv-monitoring.nl

Chamber of Commerce number: 34160453