



Dear visitor,

You regularly attend the HIV outpatient clinic for check-ups relating to your HIV infection. To give you the best possible treatment, your HIV specialist and/or nursing consultant collects your (medical) data in your medical file. With your explicit consent your data may also be used by stichting hiv monitoring (SHM) for scientific research purpose. In this letter, you will read more about the research and how you can give your consent for it.

More detailed and current¹ information can be found on our website, available in both Dutch and English: www.hiv-monitoring.nl.

Why is your data collected

Your data is used by SHM on behalf of the Center for Infectious Disease Control (Cib) of the RIVM for national HIV monitoring and for scientific research. SHM has scientific collaborations with researchers in the Netherlands, Europe and elsewhere in the world. The outcomes contribute to improving HIV care in the Netherlands.

More information about all collaborations and research can also be found on our website: www.hiv-monitoring.nl

When, where and what sort of data are collected from you and how SHM safeguards your privacy

Once you have given your explicit consent, SHM's data collector will collect relevant data from your medical file. You can withdraw your consent at your HIV treating physician or HIV nursing consultant at any time, without any consequences for your 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);
- admission and discharge date;
- data from an earlier registration with SHM, if you have previously attended another HIV treatment centre;
- hospital registration number;

Your registration data will be saved under a unique code number. Using this code number, the data collector will periodically collect your medical data which are separately 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.

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 in both Dutch and English: www.hiv-monitoring.nl



You 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.

If you are 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 available in both Dutch and English: www.hiv-monitoring.nl.

Using other data from other databases/ sources

In the interest of SHM's national HIV registration and monitoring function, the organisation may use additional data from other databases/ sources which equally cannot not directly be traced back to you. If it is necessary to establish direct data links within the treatment center database environment, SHM always works with an independent Trusted Third Party (TTP) to 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, available in both Dutch and English: www.hiv-monitoring.nl.

If you do not give consent or withdraw your given consent, then only your basic data will be registered with SHM under a unique code number so that the correct number of HIV infections in the Netherlands can be reported to Cib-RIVM. These data are:

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

Within the treatment centers, it will be noted in your file that you have not given consent or have withdrawn your consent, and your medical data will no longer be collected. However, a list is kept within the treatment team with the unique code number and hospital registration number, so SHM knows that you are included in the count of HIV infections in the Netherlands that SHM must report to Cib-RIVM. This prevents the need to repeatedly consult your medical file for this information.

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.



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

How long will your data be stored?

With your 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 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 stop collecting your (medical) data for research and anonymise your personal data.

An overview of all your rights can be found on our website, available in both Dutch and English: 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 HIV treating physician or HIV nursing consultant or you can look at the extensive information on our website, available in both Dutch and English: 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
Tafelbergweg 51
1105 BD Amsterdam

Tel: +31205664172

E-mail: privacy.shm@amsterdamumc.nl

Website: www.hiv-monitoring.nl

Chamber of Commerce number: 34160453