

Data protection notice concerning the Belgian HIV Surveillance

Sciensano - public institution with registered office at rue Juliette Wytsman 14, B-1050 Elsene, is responsible for the processing of the HIV surveillance data. The processing of the data is based on the grounds of public interest as provided for in art. 6.1 (e) of the General Data Protection Regulation, GDPR ¹ and in particular for data concerning health, for reasons of public interest in the areas of public health as provided for in art. 9.2 (i) GDPR.

As legally required for any collection of personal health-related data in Belgium, the HIV surveillance data collections were approved by the Information Security Committee (Chamber Social Security and Health) ². Their deliberation covers the framework in which the data can be processed, the measures to ensure confidentiality of data, the list of variables collected, and the secure transfer of data.

The data are collected from the Aids Reference Laboratories and the HIV Reference Centres. The data processing is technically supported by the healthdata.be-platform (<https://healthdata.sciensano.be/en/about-healthdatabe>)

Persons involved in the HIV Surveillance to whom this notice concerns:

- Newly diagnosed people living with HIV
- People living with HIV in medical follow-up
- New-borns born from mothers living with HIV
- Users of Post Exposure Prophylaxis (PEP) treatment
- Physicians who diagnosed HIV
- Physicians associated to HIV Reference Centres

¹ <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32016R0679&qid=1692268125841>

² <https://www.ehealth.fgov.be/ehealthplatform/file/view/AXGB4AUNix91GfOxg0HU?filename=14-017-f140-VIH%20et%20SIDA%20en%20Belgique-modifi%C3%A9%20le%207%20avril%202020.pdf>;

<https://www.ehealth.fgov.be/ehealthplatform/file/view/AWrArAsbgwvToiwBkgCD?filename=19-070-f132-registre%20HIV-PEP-PrEP.pdf>

Patient and physician information

Which categories of personal data does Sciensano collect for the HIV surveillance?

- Newly diagnosed people living with HIV: date of diagnosis, clinical and laboratory data on the infection at the time of diagnosis, demographical data (sex, age, nationality, postal code, country of birth), probable mode and country of infection, reason for testing.
- People living with HIV in medical follow-up: viral load measures of all people living with HIV, selected biological, immunological, clinical, treatment and death data of people living with HIV in care in the HIV Reference Centres.
- New-borns born from mothers living with HIV: viro-immunological data.
- PEP users: date of PEP treatment, demographical data (sex, age, nationality, country of birth), HIV risk exposure, HIV test result after PEP treatment.
- Physicians who diagnosed HIV and physicians associated to HIV Reference Centres: RIZIV/INAMI number.

Sciensano employees have no access to patients' identity (name, address, contact details). Only the data providers (laboratory of diagnosis and treating physician) know the full identity data. During the data transfer from the data providers to Sciensano, the national security number or other ID code used in the Aids Reference Laboratory or HIV Reference Centre is pseudonymised. This means these personal data are encoded in a way that ensures that patients can never be directly identified. This pseudonymisation is done by a so called Trusted Third Party, namely EHealth.

More detailed information regarding the data collected can be found via <https://www.healthdata.be/dcd/#/collections>

For which purpose is the HIV surveillance data used?

The processing of HIV data is done to fulfil a public health task of general interest. The collection, compilation and analysis of HIV data should make it possible to expand knowledge of the Belgian HIV epidemic. On this basis, the competent authorities will have accurate and up-to-date information to guide the management of HIV, taking into account epidemiological trends and the most recent evolutions.

Who has access to these data?

- Sciensano employees involved in the HIV surveillance have access to the pseudonymized dataset.
- Under Decision No 1082/2013/EU of the European Parliament and of the Council of October 22nd 2013 ³, Sciensano is required to report an annual pseudonymized dataset of HIV surveillance variables to the European Centre for Disease Prevention and Control (ECDC). The data transfer is done through the European Surveillance System (TESSy) ⁴.
- Reports with the results of the surveillance will be made public and will be shared with partners and federal and regional ministries of public health. These reports will only contain aggregated data (in tables).
- Sciensano may grant permission to other HIV scientists to use specific data for research purposes, if they meet strict legal and ethical requirements. Data that is shared only contains the necessary data for the relevant research. This data is securely shared.

How long will the data be stored?

The pseudonymized data will be stored for 30 years after the patient's death, in accordance with the approval of the Information Security Committee (Chamber Social Security and Health).

What rights do you have?

In carrying out its mission of HIV surveillance, Sciensano complies with the General Data Protection Regulation. Within the limits of that regulation, you have the right to:

- Consult your data
- Request a rectification of your data
- Request a restriction on the use of your data
- Oppose the processing of your data

Sciensano will only be able to respond to such requests if it is possible to link the data to the requesting individual. Since the national HIV surveillance data is stored in a pseudonymized form, it is not possible to know which data belongs to which person and Sciensano would therefore need additional information from the applicant. However, you can consult the information in your medical record and have it rectified by the treating physician.

For reasons of public interest, the General Data Protection Regulation provides exceptions to the right to request restriction of use and opposition to the processing of data.

³ <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32013D1082&qid=1692267994510>

⁴ <https://www.ecdc.europa.eu/en/publications-data/european-surveillance-system-tessy>

More information?

For more information regarding the processing of your data, please contact the Data protection Officer of Sciensano: dpo@sciensano.be

The supervising national authority may be contacted for questions or complaints at:

Gegevensbeschermingsautoriteit

Drukpersstraat 35, 1000 Brussel

02/274.48.00

contact@apd-gba.be