

Information note to set up a research data warehouse

Promoter and controller :

Dat'AIDS Association represented by its president Dr Laurent HOCQUELOUX (CHU Orléans) - contact@dataids.org

This document is given to the person taking part in the research.
This information note is available on the www.dataids.org website.

Dear Sir/Madam

You have been or are currently being followed for medical reasons in this department. In order to ensure optimal follow-up, your clinical, biological and administrative data (surname, first name, address, telephone number, etc.) (denominated as the "Data") are collected in a Nadis® computerised medical file.

Unless you object, Data from your Nadis® medical file will be transferred to the Dat'AIDS association's computerised research database known as the "research data warehouse", to be used in a national prospective cohort. The purpose of the Dat'AIDS cohort is to conduct research into the management and prevention of HIV and sexually transmitted infections (STIs) in France.

These Data may be associated with biological samples collected as part of your usual care and re-used for research purposes. The research is non-interventional, known as "data-based", but helps to address general questions for better management and prevention of HIV and STIs.

The legal basis for processing your Personal Data is the legitimate interest of the Dat'AIDS association in this warehouse and its operation.

The confidentiality of Data relies on identity coded by means of a serial number or an alphanumeric code. Analyses will always be carried out confidentially on coded data, without mentionin full name, and the results will be completely anonymous.

All of our Searches comply with the French Data Protection Act of 6 January 1978 as amended and Act No. 2018-493 of 20 June 2018 on the protection of personal data and Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of individuals with regard to the processing of personal data and on the free movement of such data (the "GDPR").

The Dat'AIDS association's research data warehouse was authorized by the CNIL on 19/06/2024 (decision DT-2024-012).

Data collected

Data collected includes care centre, civil status (gender, month and year of birth, country of birth, department of residence), personal life characteristics (family situation, lifestyle habits, level of education), profession, health status, sexual characterisitics (HIV ans STIs screening, sexuality, mode of contamination) and hospital visits (consultation or hospitalization).

Recipients

The categories of persons described below have access to the Data processed, within the limits of their authorizations with regard to their functions and under conditions that comply with the regulations. These categories of persons are subject to professional secrecy under the conditions defined by articles 226-13 and 226-14 of the French Penal Code.

Will have access to the data warehouse:

- the data manager for the creation of databases
- methodologists responsible for data analysis
- the service providers responsible for hosting the data and maintaining the server on which the Data is stored.

This warehouse is set up in collaboration with other centres in France (the list of centres is available on dataids.org).

We ensure that our external service providers offer sufficient guarantees regarding the implementation of appropriate technical and organizational measures so that the processing of Data meets the requirements of the GDPR, the Data Protection Act and guarantees the protection of rights.

Transfers

No personal data is transferred outside the European Union.

Data retention

Data is kept for up to 20 years after the date of collection by the Dat'AIDS association. Data is then destroyed.

Security

We take all necessary and useful precautions to preserve the security of Data, in particular its confidentiality, integrity and availability. Our data storage and sharing service providers are certified (health data host, ISO standard, etc.).

Your rights

In accordance with the provisions of the French Data Protection Act and the GDPR, you have the right to access your Data. You also have the right to give instructions concerning your data after your death.

In accordance with the provisions of Article 16 of the GDPR, you have the right to obtain from the controller, as soon as possible, the rectification of inaccurate personal data and its completion, including by providing a supplementary declaration.

If you wish to object to the use of your data, you can, at any time and without justification express your objection by any means to the person responsible for the data warehouse, in accordance with the French Data Protection Act. This will have no effect on the quality of care you receive.

The right to erase data is provided in Article 17 of the GDPR and applies when you exert your right to object and erase your data collected. Subject to appropriate prior information by the data controller, certain data previously collected may not, however, be deleted if such deletion is likely to make it impossible or seriously compromise the research. The right to limit processing provided for in Article 18 of the GDPR is exercised in accordance with the provisions of this article.

If you wish to exert any of your rights, simply inform the Data Protection Officer (the "DPO") of the Dat'AIDS Association at dpo@dataids.org, indicating your care centre.

We process your request within a maximum of one month after receipt. This period may be extended by two months, depending on the complexity and number of requests. You will be notified of this extension within one month of request receipt.

If you are not satisfied with the way we process your Data, you can also lodge a complaint with the CNIL: www.cnil.fr/fr/plaintes).

List of studies

The list of research on data in this warehouse can be consulted on the dataids.org website, in the "Scientific projects" section.