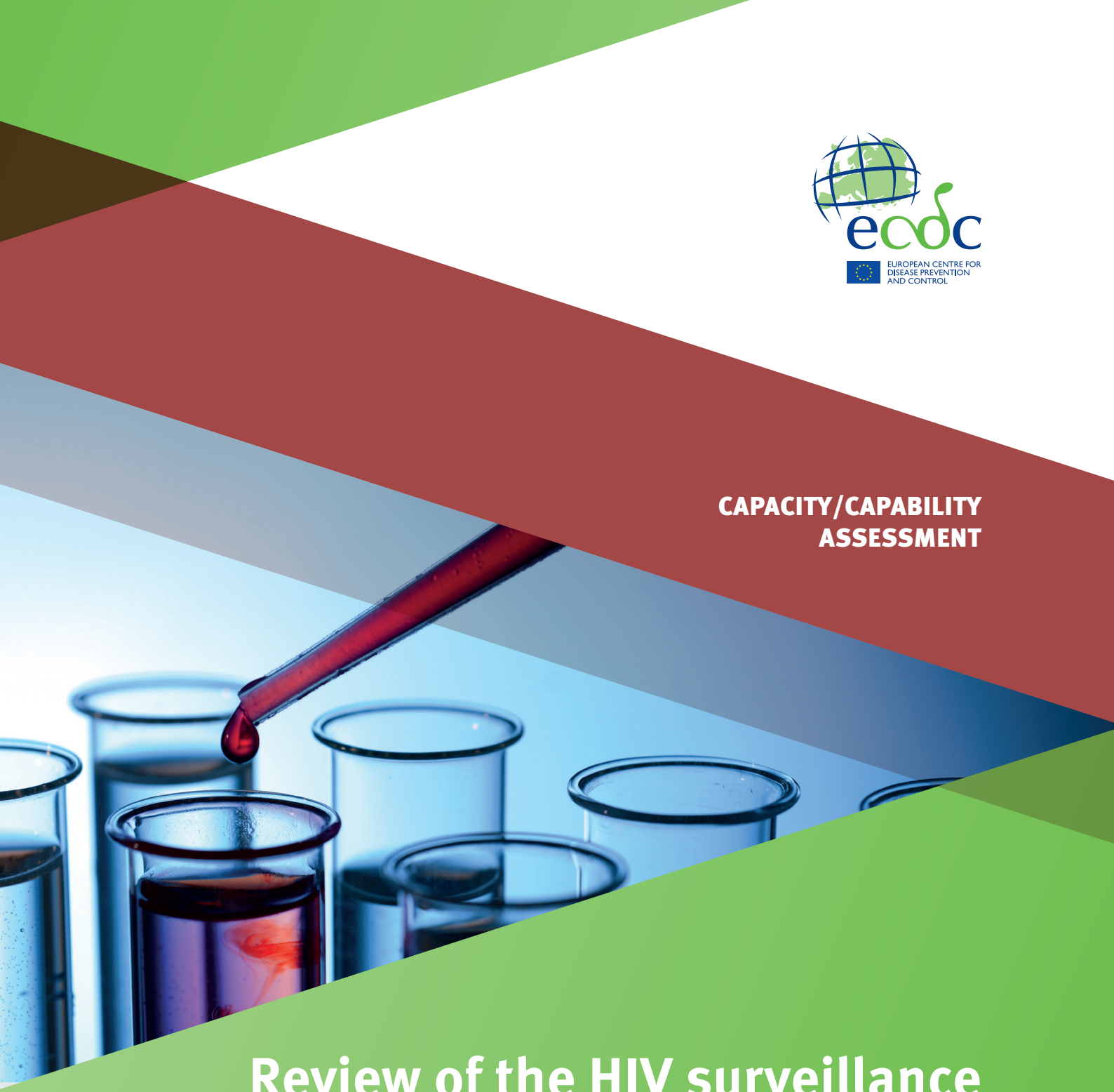

CAPACITY/CAPABILITY ASSESSMENT

Review of the HIV surveillance system in France

November 2024

ECDC CAPACITY AND CAPABILITY ASSESSMENT

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This report from the European Centre for Disease Prevention and Control (ECDC) was coordinated by Anastasia Pharris and Juliana Reyes-Urueña, with the support of Viviane Bremer from the Robert Koch Institute in Germany and Jean-Michel Thiolet, a public health expert and consultant from France. Colleagues from Santé publique France also provided input and fact-checked the system description for accuracy. The report was submitted by ECDC to Santé publique France in June 2024 and is published with the agreement of Santé publique France.

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Contents

Abbreviations

ARS	Regional Health Agency (Agence Régionale de Santé)
CNS	National AIDS and Viral Hepatitis Council (Conseil national du sida et des hépatites virales)
COREVIH	Regional Coordination for Combating the Human Immunodeficiency Virus (Coordination Régionale de lutte contre le Virus de l'Immunodéficience Humaine)
FHDH	Hospital Database on HIV
HIV	human immunodeficiency virus
LABOé-SI	electronic reporting tool for laboratories
MSM	men who have sex with men
PLHIV	people living with HIV
PrEP	pre-exposure prophylaxis
PWID	people who inject drugs
SNDS	French National Health Data System (Système National des Données de Santé)
SNSS	National Sexual Health Strategy (Stratégie Nationale de Santé Sexuelle)
STI	Sexually transmitted infection

Executive summary

HIV has been a nationally notifiable disease in France since 2003. An online reporting system for the disease was introduced in 2016. The original aims of the HIV surveillance in France were to estimate new diagnoses and monitor key indicators such as HIV incidence and the continuum of care, although it is recognised that these objectives need to be updated. A 2019 review by Santé publique France identified challenges, worsened by COVID-19, leading to under-reporting of cases. The French National Sexual Health Strategy (SNSS) launched in 2017 integrates HIV into broader sexual health priorities. Significant changes to the system are being considered, including an overhaul of the online reporting system. The European Centre for Disease Prevention and Control (ECDC) was asked to review the system to benchmark it against other European systems and provide recommendations for its improvement. Data for the assessment were collected through a desk review, benchmarking exercises, and stakeholder interviews. The desk review covered publicly available resources and documents from stakeholders. The benchmarking exercise involved a survey of EU/EEA HIV surveillance focal points and a review of data submitted by France to ECDC. During the country visit and through virtual interviews, the team engaged with 47 persons from Santé publique France as well as external stakeholders, gathering background information and perspectives on the current system and potential future adaptations.

The assessment found that the HIV surveillance system remains crucial for monitoring and informing HIV prevention and care services. Highly valued by stakeholders, it provides essential data for guiding the HIV response. Stakeholders appreciate the work of Santé publique France and support the SNSS strategy. France benefits from rich data sources and skilled experts. However, a modernisation of the HIV surveillance system in France is needed to meet evolving demands. The HIV surveillance objectives and reporting protocols are outdated and not aligned with current needs. Despite significant resources, the system fails to provide timely data, leading to mistrust and questions about data validity. Underreporting is high, and stakeholders do not fully understand the adjustments made to account for it. HIV estimates are not updated regularly, and regional stakeholders feel disconnected from the whole process of data collection, analysis, and validation. The e-DO system is nearly obsolete, requiring major changes for compliance with data protection laws and improved functionality. Additionally, there is an imbalance between the staffing levels and workload of the Santé publique France HIV team.

Several areas for improvement were identified for the consideration of the Ministry of Health, Santé publique France, and other actors.

- Strengthen coordination: Enhance the Ministry of Health's coordination of HIV data to better integrate strategic information from various sources and improve public health outcomes. This includes a more effective use of existing resources like the Regional Coordination for Combating the Human Immunodeficiency Virus (COREVIH) system and regional data partnerships.
- Enhance stakeholder engagement: Increase communication and engagement with stakeholders through regular two-way discussions, dashboards, alerts, and a dedicated space for data insights. This will boost data quality and stakeholder motivation.
- Upgrade the e-DO system: Prioritise significant updates or a complete rebuild of the e-DO system to improve functionality, security, and interoperability with electronic health records. Simplify the authentication process and ensure integration with old data to prevent data loss.
- Leverage regional actors: Strengthen the role of COREVIH and other regional actors in improving data quality and completeness. Ensure regional data are available in a timely manner to inform local public health efforts.
- Update surveillance objectives: Review and update HIV surveillance objectives to align with current needs and stakeholder inputs. Modify data collection to focus on relevant variables and discontinue less useful practices like the current approach to recency testing and under-reporting adjustments.
- Generate timely estimates: Continue prioritising the generation of estimates for HIV incidence, time from infection to diagnosis, and the undiagnosed population. Present results early and maintain continuous dialogue with stakeholders.
- Future-proof the system: Simplify data capture using efficient methods like the LABOé-SI system and enhanced use of SNDS data. Ensure the system can adapt to future needs with easier data extraction from electronic systems.

Background

HIV has been a nationally notifiable disease in France since 2003, undergoing a transition from paper forms to an online reporting system in 2016. The main objectives of the HIV surveillance in France are to efficiently estimate the number of new HIV diagnoses and then to carry out annual estimates of other key indicators (e.g. HIV incidence, continuum of care), although the formal objectives of the surveillance system have not been reviewed and updated for some time. An internal review of the French HIV surveillance system performed by Santé publique France in 2019 revealed certain challenges, which were exacerbated by the COVID-19 pandemic which heightened non-participation of biologists and physicians in the French HIV reporting systems, worsening under-reporting.

The French National Sexual Health Strategy (SNSS) was designed and launched in 2017, with plans for implementation until 2030 [1]. This comprehensive strategy incorporates HIV within a broader framework of sexual health priorities. Among other sources, HIV surveillance data are used to evaluate progress and redirect the next steps for the SNSS strategy. Generating this data in a timely manner is a priority for the HIV surveillance system as per the Ministry of Health, which coordinates the SNSS.

In parallel, in a context of budgetary and human resource constraints, significant changes to the current system are under consideration by Santé publique France, including a planned overhaul of the online system for notifying HIV and AIDS cases and a possible evolution of virological surveillance activities away from the nation-wide use of a recent infection assay.

Purpose and objectives

Based on a request from Santé publique France, ECDC was asked to conduct an external review of the French HIV surveillance system to provide recommendations and promote alignment of all proposed modifications.

The main objectives of this review included:

- To benchmark the HIV surveillance system and objectives against other European systems and EU reporting requirements, and to determine opportunities for improvement.
- To provide recommendations to strengthen and streamline the HIV surveillance objectives and system, with a view of maximising the system's efficiency and usefulness to the needs of the Ministry of Health and other stakeholders.

Methods

The assessment collected data and information based on the following three main activities:

- Desk review
- Benchmarking
  - Survey of EU/EEA HIV surveillance focal points
  - European HIV surveillance and monitoring reporting
- Country visit and stakeholder interviews.

Desk review

The desk review was non-systematic and covered both publicly available resources (published articles, reports, data) and documents requested and received via Santé publique France and other stakeholders (Annex 1).

Benchmarking

The benchmarking exercise was based on a survey of EU/EEA surveillance focal points and on a review of data submitted by Santé publique France to the most recent calls for HIV surveillance (2022 data) and Dublin declaration monitoring (2023/4 data).

Survey of EU/EEA HIV surveillance focal points

The main objective of this survey was to characterise and map the current surveillance systems for HIV/AIDS in the EU/EEA and identify improvement points for the system in France. The specific objectives included benchmarking existing surveillance systems to identify best practices and standards in HIV/AIDS surveillance, with the aim of pinpointing areas for alignment and improvement.

The framework used was based on the OASIS methodology [2]. A set of 107 questions assessed the organisational and functional aspects of a HIV surveillance system.

Organisational attributes included an assessment of the organisational structures and management of the surveillance system including the existence of clear, relevant objectives, the existence of a steering committee and clearly defined roles and responsibilities, financial and human resources, stakeholder involvement and the existence of effective processes for data management and dissemination of information.

Functional attributes included representativeness, timeliness, acceptability, simplicity and usefulness.

The questionnaire was distributed via a Redcap link to the national surveillance focal point of each EU/EEA country. Of the 30 EU/EEA countries surveyed, 24 responded by the cut-off date. The relevant results for France were extracted for this report, however a full report of the survey with detailed results for all countries will be published by ECDC.

European HIV surveillance and monitoring reporting

The completeness of key variables (age, gender, transmission, CD4 cell count at diagnosis, country or region of birth and previous positive HIV status) submitted to the European Surveillance System (TESSy) for 2022 diagnoses were calculated for France and compared to EU/EEA averages [3].

Responses by France to the Dublin Declaration questionnaire on monitoring HIV for 2023 and 2024 on indicators and data related to the HIV continuum of care were compared to responses from countries in the region [4].

Country visit and stakeholder interviews

The key part of the assessment was an in-country mission. The evaluation team consisted of HIV surveillance experts from ECDC, Germany and an expert on the French public health system.

- Viviane Bremer, Head of unit for HIV/AIDS, STI and hepatitis, Robert Koch Institute, Germany;
- Jean-Michel Thiolet, Public health expert and consultant, France;
- Anastasia Pharris, Principal expert in infectious diseases, ECDC;
- Juliana Reyes-Urueña, Expert infectious diseases, ECDC.

The mission occurred between 12–14 March 2024. The programme for the country visit was developed in close collaboration with Santé publique France and is displayed in Annex 2.

The team met with and received input from a broad range of Santé publique France staff and external stakeholders (totalling 47 individuals) during the country visit, as well as through virtual interviews that took place in the weeks before and after the mission. Interviews took place in English or French, depending on the preference of the interviewee. A detailed list of the individuals interviewed and the organisations they represent is provided in Annex 3.

All key stakeholders with whom a meeting or an interview was planned were provided with questions ahead of time. These questions differed by stakeholder and aimed to provide background and perspectives on the current functioning and future possible adaptations to the French HIV surveillance system.

A first draft of the report was shared with Santé publique France to fact-check accurate description of the HIV surveillance system. Their revision did not modify the suggestions for improvements or final conclusions.

Findings

This section describes the HIV surveillance system before reporting on the findings gathered through the desk review, benchmarking exercise, and stakeholder interviews. The findings from these various sources are integrated under the following categories: surveillance system characteristics and objectives; tools and technical resources; data quality; acceptability; usefulness; simplicity; representativeness, timeliness; and communication and evaluation processes.

Description of the HIV surveillance system

The French HIV surveillance system is coordinated by Santé publique France and consists of:

- Mandatory reporting of HIV infection and deaths in HIV (non AIDS) infected people;
- Mandatory reporting of AIDS and deaths in people with AIDS;
- HIV virological surveillance;
- HIV testing surveillance.

Mandatory reporting of HIV infection

Mandatory reporting of HIV infections was put in place in 2003, while the online electronic application (e-DO) was introduced in 2016. Biologists and clinicians can notify the diagnoses on the e-DO application themselves or designate the persons they authorise to notify cases under their responsibility. Both the healthcare professional and the person authorised must have a personal identification card and the card reader installed on their computer. To date, the application has 575 active profiles of authorised persons.

The biologist diagnosing the HIV infection and the clinician prescribing the HIV test or initiating care of the patient should in parallel both notify the case in the e-DO system. If only one declaration (biologist or clinician) is received for a given serology, a reminder is sent to the other party indicated in that declaration (clinician or laboratorian, or their authorised persons).

The data collected include demographic, epidemiological, and clinical factors. In the event of missing essential information on the forms, inconsistencies or incomprehensible elements, Santé publique France will request additional information from the declarant (or authorised person). These operations are carried out via e-DO or on paper if the declarant does not have access to e-DO.

HIV reporting is pseudonymised at the source, i.e. at the level of the reporter. It includes an anonymity code as an identifier, created directly by the declarant in the e-DO (or by means of the anonymisation software provided by Santé publique France if the declaration is made on paper). It is an irreversible code, established by the declarant from the initial of the patient's surname, first name, date of birth and sex (at birth). Unless the declarant is mistaken on these elements, a patient declared by several healthcare professionals always has the same anonymity code, which allows Santé publique France to link all the declarations concerning the same person. Santé publique France oversees matching the various forms transmitted (clinical and biological notifications) and identifying any duplicates.

Data reported by the clinicians and biologists (as depicted in Figure 1) are directly transmitted through the e-DO system to Santé publique France at the national level. Regional health authorities (ARS) and regional Santé publique France staff have read-only access to the e-DO application.

The death of a person living with HIV is also notifiable, and is done by the clinician, on a specific form in e-DO, or on the HIV form if the report is made on paper. Whereas HIV deaths were largely under-reported before e-DO (so that these data were not published), they have been increasingly reported since the programme's introduction.

Mandatory reporting of AIDS infection

AIDS diagnoses, whether or not the patient's HIV status is already known, are also subject to mandatory reporting, by the clinician only (or person authorised). Similar to HIV reporting, AIDS is reported online via e-DO. When the diagnosis of AIDS is concomitant with the diagnosis of HIV infection, both events are reported on the same HIV/AIDS form.

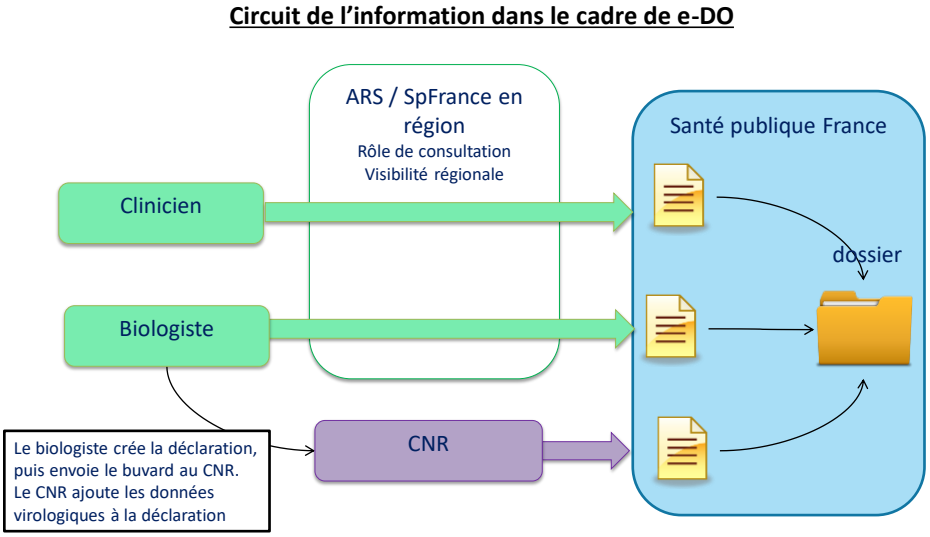
The death of a person at AIDS stage is also notifiable and is done by the clinician (or person authorised), on a specific form in e-DO, or on the AIDS form if the report is made on paper.

Notification of AIDS cases sometimes leads to the notification of an HIV case that was previously missed. Furthermore, incomplete or 'biological only' HIV reports may subsequently be supplemented by information from an AIDS report.

HIV virological surveillance

In addition to the mandatory reporting of HIV, virological surveillance is carried out by the associated laboratory of the National Reference Centre (NRC for HIV) at Tours University Hospital, enabling the surveillance of the evolution of rare types and groups of the virus circulating in France and the proportion of recent HIV-1 infections. The NRC carries out the analyses on a sample taken from the tube used for HIV diagnosis, blotted by the biologist who sends it to the NRC with a copy of his declaration containing the anonymity code. Once the analyses have been carried out, the NRC enters the results directly into e-DO, on the basis of the anonymity code.

Figure 1. HIV notification dataflow in France



Source: Santé publique France
Notes : SpFrance=Santé publique France; CNR=National Reference Laboratory ; ARS= Regional Health Agency (Agence Régionale de Santé)

Several types of support have been put in place to help e-DO users. They include a dedicated page on the Santé publique France website, which can also be accessed via a direct link on the first screen of e-DO (before or after logging in), with explanations and tutorials. There is also a dedicated telephone support. However, this is planned to be discontinued at the end of 2024.

HIV testing surveillance

The activity of HIV testing in medical analysis laboratories is monitored by a survey repeated every year among all laboratories (LaboVIH) with more than 4 000 laboratories participating in 2023, organised into almost 600 groups, that take samples for HIV serology, even if the serology is not processed. The number of all HIV serologies carried out in laboratories (excluding serology tests performed during a blood donation) and the number of people confirmed positive for the first time by the laboratory are collected. The number of serologies performed in an anonymous setting is collected separately. The methods for collecting these data have varied over time and data collection for 2023 is done either by e-DO or by a personalised form sent by email. Before 2022 it was increasingly difficult to maintain adequate participation in the survey due to COVID-19 and the outsourcing of data collection. The data collection conducted in 2024 for 2023 was much less time-consuming for Santé publique France but remained equally time-consuming for the biologists themselves. Participation in LaboVIH decreased sharply during the COVID-19 pandemic period but has risen again since 2023.

Further to the LabovHIV survey, the number of rapid diagnostic tests carried out as part of 'community' screening actions is collected in aggregate by the Directorate-General for Health (DGS), based on the annual activity reports of the subsidised structures. The number of self-tests sold is monitored by Santé publique France by self-test sales data. Surveillance of HIV testing and diagnosis within the Free Information, Screening and Diagnosis Centres for Human Immunodeficiency Virus Infections, Viral Hepatitis and Sexually Transmitted Infections (CeGIDD; set up on 1 January 2016) using individual data (file extracted from their software) was set up by Santé publique France. Aggregated data are also available via annual reports the centres provide to the ARS of their region, through a dedicated application. The national data are extracted by the DGS and made available to Santé publique France.

Data adjustments

For analysis and communication purposes, the number of HIV declarations received is adjusted each year by Santé publique France. The adjustment method used before COVID-19 was reported by Santé publique France to produce less accurate results in some regions, and the approach was thus reviewed and adjusted. The current approach to adjustments takes into account:

- Reporting delay: to avoid a false decline at the end of the period analysed, the approach assumes that the reporting delay distribution is stable over time, after stratification by paper or online report.
- Missing data: some data are missing from the reports, particularly when the case is reported only by the biologist, without a report from the clinician. However, clinical data are often necessary to distinguish new seropositive cases from those already known, or to characterise them. Multiple imputation is therefore implemented to complete the database. The imputation methods were reviewed in 2023 and a number of changes were made using semi-parametric or non-parametric methods.
- Selection of new diagnoses: from the imputed database, diagnoses reported 'without a previous positive test' or with a previous positive test less than 12 months ago are defined as new HIV diagnoses in the year that the report was notified.
- Under-reporting: under-reporting is defined as the probability that a confirmed serology is not reported by a biologist or by a clinician. Under-reporting is calculated for a given year by comparing the number of reports of HIV either by a biologist or a clinician, or both (after correction for delays, and including duplicates) with the number of non-anonymous confirmed positive serologies estimated from LaboVIH. Several alternative methods to correct for under-reporting were tested in 2023, including the use of the SNDS or data from a sample of laboratories to replace the full LaboVIH results. However, to-date, none have proved conclusive. Since 2023, under-reporting has been calculated separately for HIV serology performed both inside and outside hospitals.

Data published in the national bulletin are mainly adjusted data, whereas each regional bulletin includes both adjusted data for the total number of cases, and raw data for case description. AIDS case description is only based on raw data as there are little missing data in AIDS reports.

Surveillance system characteristics and objectives

Organisational attributes of the surveillance system

This section mainly reports on the survey results submitted to EU/EEA focal points. Where specified, it also includes selected information from stakeholder interviews when relevant to the topic presented.

Structure, documentation, and composition of the HIV surveillance system

The organisational and functional attributes assessed in this report through benchmarking are thoroughly described and analysed in various sections throughout the document. However, Table 1 in Annex 4 describes the results of all assessed attributes in a single table. Table 1 below summarises the results of the structure, documentation, and composition of the HIV surveillance system, as described in this section, obtained from benchmarking France and 24 EU/EEA countries.

Table 1. Summary of structure, documentation, and composition of the HIV surveillance system: benchmarking between France and 24 EU/EEA countries

*	Surveillance system characteristics and objectives	France	EU/EEA (24 countries)
	Surveillance objectives up-to-date	Surveillance objectives are self-assessed as not up-to-date or in concordance with the current context and need for information	All but three EU/EEA countries self-assess their surveillance objectives as in accordance with the current context and need for information, although some denote minor deficiencies. France along with two other countries report major deficiencies
	Steering committee in place	No committee in place	11/24 EU/EEA countries report having a surveillance steering committee in place
	Surveillance protocols in place and up-to-date	Surveillance protocol in place but not up-to-date	12/16 EU/EEA countries with protocols in place report that the protocol is up-to-date
	Number of staff working in the HIV surveillance system	0.09 per one million population	EU/EEA average is 5.7 per million population
	Adequate human resources for HIV surveillance	Self-assessed as insufficient	About 1/3 of EU/EEA countries (7/22) report that resources are insufficient
	Financial resources for centralised team and database management	Self-assessed as insufficient and severely limiting surveillance activities	No other EU/EEA country reports major financial inadequacies for both the centralised team and database management that severely limit surveillance activities

**Red=major issues noted as compared to other EU/EEA countries and European surveillance standard; Yellow=some deviations or areas where closer examination may lead to improvements.*
The data in this table for countries other than France are provisional. Therefore, slight changes in the data displayed for those countries could occur when the full report from the Survey of EU/EEA HIV surveillance focal points is published.

Among the 24 countries responding to the survey, 19 indicated the presence of a national network, where decisions regarding the surveillance system are made at the national level, including France.

Twenty-one countries, including France, have defined objectives for their HIV surveillance systems. Table 2 shows the country's assessment of surveillance system objectives in relation to the current HIV context and information needs. France is one of three countries in which the surveillance objectives are in accordance with the current context and need for information about HIV, but there are major deficiencies. Fifteen countries, including France, are planning to update their HIV surveillance objectives.

Regarding the documentation of the surveillance system, 22 of the 24 responding countries stated that the HIV surveillance system is formalised within national legislation. Seventeen countries reported having a document that comprehensively defines the roles of different partners within the surveillance network, five do not have any such documents, and two either do not know or did not respond to this question. France has formalised the HIV surveillance system; however, it lacks a document that describes the roles of all the partners within the surveillance network.

Table 2. Country assessment of surveillance system objectives concerning current HIV context and information needs

The objectives are still in accordance with the current context and need for information about HIV	The objectives are still in accordance with the current context and need for information about HIV but with minor deficiencies	The objectives are in accordance with the current context and need for information about HIV but there are major deficiencies
Cyprus	Belgium	Germany
Czechia	Croatia	Portugal
Finland	Denmark	France
Italy	Estonia	
Netherlands	Greece	
Romania	Ireland	
Slovenia	Liechtenstein	
Sweden	Luxembourg	
	Norway	
	Spain	

Three countries did not respond to this question.
The data in this table for countries other than France are provisional. Therefore, slight changes in the data displayed for those countries could occur when the full report from the Survey of EU/EEA HIV surveillance focal points is published.

Eleven countries reported having a steering committee in place, defined as the entity playing a pivotal role in deciding the orientations and objectives of the network, as well as making strategic decisions. It comprises the main decision-making bodies involved in surveillance. Conversely, twelve countries, including France, do not have this group established.

In stakeholder interviews, it was emphasised that France has plentiful sources of data to inform and evaluate the HIV response, including comprehensive surveillance, HIV cohorts, national insurance and prescription data, and data compiled by regions, such as the regional Santé publique France actors, ARS and the COREVIH, but that nobody is coordinating or synthesising data from all of these sources, or prioritising where data improvements are required. It was seen to be the mandate of the Ministry of Health to enhance their emphasis in this area, with the support of Santé publique France and other actors.

Sixteen countries, including France, reported having a documented surveillance protocol for reporting cases within their respective countries. Among those countries with a reporting protocol in place, France was one of a minority of countries that indicated that the protocol was not updated. Twenty countries reported using the ECDC definition for HIV, while France and Sweden employ a distinct one. The case definition for HIV in France does not consider positive results from two EIA antibody tests confirmed by a positive result from a further EIA test. In France, a confirmation test is required, and it cannot be another EIA.

Twenty-one countries, including France, indicated having a centralised team or organisation responsible for overseeing the entire HIV surveillance system. The activities carried out by the centralised team or organisation include data analysis (21 countries including France), communication of results (21 countries including France), data management (20 countries including France), data validation (19 countries including France), and modelling (i.e. generating incidence estimates, or people living with HIV estimates) (15 countries including France).

Human and financial resources

When asked about the adequacy of human resources within the centralised team, eight countries indicated that resources were just sufficient, while seven reported that they were barely sufficient. Additionally, seven countries, including France, reported that the resources were insufficient.

In stakeholder interviews, concern was expressed by multiple stakeholders about the imbalance between the amount of staff and the tasks at hand for the HIV team at Santé publique France. The recruitment of a modeller to coordinate work on HIV estimates was emphasised by many stakeholders as a very important priority.

In terms of resources, Table 3, shows a comparative assessment of financial resource adequacy for the centralised team and database maintenance, by country. Notably, France was the only country to report major financial inadequacies for both the centralised team and database maintenance, severely limiting surveillance activities.

Table 3. Comparative assessment of financial resource adequacy for the centralised team and database maintenance by country

	Financial resources for the centralised team	Financial resources to maintain the database
Austria		
Belgium		
Croatia		
Cyprus		
Czechia		
Denmark		
Estonia		
Finland		
France		
Germany		
Greece		
Ireland		
Italy		
Liechtenstein		
Lithuania		
Luxembourg		
Malta		
Netherlands		
Norway		
Portugal		
Romania		
Slovenia		
Spain		
Sweden		

The financial means are considered sufficient
No and deficiencies are minor, these deficiencies generate a constraint on the structure but do not interfere with the conduct of the surveillance activities
No and deficiencies are medium, deficiencies create a constraint that interferes with the conduct of the surveillance activities
No and deficiencies are major, deficiencies create a constraint that severely limits the conduct of the surveillance activities
Missing information

The data in this table for countries other than France are provisional. Therefore, slight changes in the data displayed for those countries could occur when the full report from the Survey of EU/EEA HIV surveillance focal points is published.

Regarding resources, including both financial and technical aspects such as data collectors and established databases to facilitate the effective reporting of new HIV diagnoses by clinicians and laboratories, 11 countries reported having sufficient resources, while 10, including France, reported they do not.

Tools and technical resources

Table 4 summarises the results of tools and technical resources of the HIV surveillance system, as described in this section, obtained from the benchmarking between France and the other 24 EU/EEA countries.

Table 4. Summary of tools and technical resources HIV surveillance system: benchmarking between France and 24 EU/EEA countries

*	Tools and technical resources	France	EU/EEA (24 countries)
	Database access and/or dashboard available to assist clinicians and laboratories in managing the data effectively	Clinicians and biologists have to enter their reports manually in e-DO. There is an e-DO dashboard, however it is purely an informational tool and does not assist clinicians and biologists in managing their reports. It only shows the number of reports (not the number of people diagnosed).	11/24 responding EU/EEA countries enable database access for clinicians and laboratories reporting data 4/22 have a dashboard for this purpose
	Percentage of laboratory data that can be linked with epidemiological data	51-75% (When both clinician and laboratory reports exist, they can be linked (unless there are major issues with inputting data for the anonymity code). The problem lies in underreporting, which results in some lab reports having no corresponding clinician report).	Most EU/EEA countries can link >75% of laboratory and epidemiological data
	Structured data management processes in place	Yes	22/24 EU/EEA countries have processes in place
	Can link to other sources of information based on personal identifier used to report HIV cases	No (limitation requested by the CNIL)	11/24 countries can link to information from other sources
	Can identify and eliminate duplicate cases	Yes	20/24 countries can identify and eliminate duplicates

**Red=major issues noted as compared to other EU/EEA countries and European surveillance standard; Green=areas where the system is performing well and in line with or above the EU/EEA average.*
The data in this table for countries other than France are provisional. Therefore, slight changes in the data displayed for those countries could occur when the full report from the Survey of EU/EEA HIV surveillance focal points is published.

France has several actors and data sources available which are related to HIV surveillance that will be presented here, including COREVIHs, HIV cohorts, health insurance data, and the LABOé-SI system. The existing system for mandatory reporting will be described in this section.

Regional Coordination for Combating the Human Immunodeficiency Virus

Regional Coordination for Combating the Human Immunodeficiency Virus (COREVIHs) are regional HIV/AIDS coordinating committees. They were officially set up in 2007 and are headquartered in the main university hospital centres in each region (except for Ile-de-France [IdF], where there are five of them). There are three regions with several COREVIHs: IdF, Provence-Alps-Cote d'Azur (PACA) and Auvergne-Rhône-Alpes (ARA). Its members are appointed by the Agence Régionale de Santé (Regional Health Agency) and include people involved in research, care, prevention and screening, both inside and outside hospitals, as well as members of associations representing patients and users of the healthcare system. The COREVIHs are funded by the Ministry of Health.

The three main missions of the COREVIHs are based on the recommendations made in 2006 and reviewed in 2017:

- To promote the coordination of healthcare professionals involved in the fight against HIV;
- To help improve the quality and safety of patient care, and to evaluate and harmonise practices;
- To analyse medical and epidemiological data of HIV-infected patients. As part of this, COREVIHs implemented the French Hospital Database on HIV (FHDH) HIV cohort database, which is fed from interfaces with specialist medical records, such as NADIS. Nadis is the electronic tool widely used by HIV clinicians to gather patients' clinical records and also serves as a tool to gather cohort data. Data are automatically extracted from clinical records, making data collection an automated process. Nadis displays the necessary data for notifications on one screen, allowing technicians to view all e-DO information in a single screenshot for easier access and notification purposes. Initially, this data collection was intended to enable COREVIH to take part in the analysis of data in their area. Around two thirds of the centres participating in the FHDH use Nadis, the others use other tools such as Diamg or Orbis.

To carry out these tasks, each COREVIH has several employees, generally an administrative and medical coordinator and clinical study technicians (TECs), who were initially mainly responsible for collecting data for the FHDH cohort database. The organisation of HIV mandatory declaration (DO) is subject to specific regulatory provisions relating to the support role of COREVIHs in the operation of the system. A 2018 instruction reaffirmed the mission of COREVIHs to ensure that healthcare professionals adhere to mandatory reporting of HIV/AIDS, via e-DO, to improve its exhaustiveness. Activities across COREVIHs vary substantially, including their involvement with mandatory notification of HIV cases.

Projects within the COREVIH Nouvelle Aquitaine and the COREVIH PACA Est, for example, on data improvement and local analysis of the regional epidemiological data were initiated with success. Currently, a review of COREVIH activities is ongoing, coordinated by the Ministry of Health and a revised mandate for their activities is expected.

COREVIH and the hospitals it coordinates are responsible for the majority of reports of HIV infection, however 25% of reports at the national level come from establishments that are not part of the COREVIHs' local data in its current configuration.

HIV cohorts

France has two large HIV cohorts: HIV ANRS CO4 and Aquitaine ANRS CO3, both of which receive funding through the French research and public health system. These cohorts cover the majority of people living with HIV in France, providing information to the French HIV cohort database on treatment outcomes as well as measures of at least one indicator of the HIV continuum of care. Currently, a review of HIV cohort scope and mandate is ongoing, coordinated by ANRS.

Health insurance data

Data from the French National Health Data System (SNDS) covers nearly 100% of the French population, including private clinics. The system collects information on prescribed test and drug reimbursements from doctors, including new antiretroviral treatment. The SNDS data contains information on gender, date of birth, place of residence and socio-economic level, but does not contain information on transmission mode, time of diagnosis or migration background. SNDS data are available with a three-month time lag. SNDS data can be linked with other data sources when approved by the CNIL. When a comparison was made between SNDS and HIV data obtained through the mandatory notification system, SNDS data generally showed the same trend over time but with regional variation. This data set is also used by EPI-PHARE to evaluate the progression of PrEP prescriptions in the country.

LABOé-SI

Created in the context of the COVID-19 pandemic, the population screening information system (SI-DEP) paved the way for an automated reporting system of for laboratory results. The new iteration, LABOé-SI will allow the reporting of certain screening activity and test results by laboratories, first focusing on SARS-CoV-2 and then gradually integrating other pathogens, with the objective of strengthening epidemiological surveillance, simplifying reporting and instituting a digital link in the national system for preparing and managing health crises. This system has now been implemented in a legal decree [5] with an accompanying legal order [6]. Given that HIV is listed in the decree, many stakeholders mentioned the possible application of this system to HIV, allowing eventual automated reporting of laboratory notifications to occur more timely and efficiently, replacing LaboVIH and continuing HIV testing surveillance in a more systematic and automated manner. The timeline for the implementation of this HIV system is not clear and will be determined by the Ministry of Health.

Mandatory notification system for HIV

Table 5 describes the resources available to aid clinicians and/or laboratories in effectively managing data by country. Seventeen countries have a case notification form for reporting, 11 countries offer direct database access for reporting, and four countries have dashboards that display data to clinicians and laboratories. France has a case notification form in place for clinicians and laboratories, but this does not enable database access of the clinician's' own reports or regional data or dashboards to support reporting or to provide feedback.

Table 5. Resources available to assist clinicians and laboratories in managing data effectively, by country

	Case notification form	Database access	Dashboards	Other
Austria				
Belgium				
Croatia				
Cyprus				
Czechia				
Denmark				
Estonia				
Finland				
France				
Germany				
Greece				
Ireland				
Italy				
Liechtenstein				
Luxembourg				
Malta				
Netherlands				
Norway				
Portugal				
Romania				
Slovenia				
Spain				
Sweden				

Green shading indicates that this resource is available and used for data management; Lithuania did not respond to this question.
The data in this table for countries other than France are provisional. Therefore, slight changes in the data displayed for those countries could occur when the full report from the Survey of EU/EEA HIV surveillance focal points is published.

Twenty-two countries reported having a centralised database within their national surveillance system, including France. In addition, 12 countries have implemented an electronic reporting system that automatically gathers and sends data to the centralised database, while other countries rely on traditional paper-based reporting forms, which healthcare facilities submit to regional and national health departments.

Countries with laboratories reporting to HIV surveillance systems

From the 16 countries where laboratories are reporting, five have automated reporting systems. Conversely, in France and three other countries, reporting from laboratories requires manual entry by laboratory staff. The percentage of laboratory data that can be linked with epidemiological data is less than 25% in Estonia, approximately 51-75% in France, and over 75% in the remaining countries, except for Malta and Portugal where the percentage is unknown.

The primary barriers to linking laboratory data, as reported by countries, vary significantly. In France, the main reason for not being able to link biological and clinical data, is that either clinician or biologist does not declare the case, whether the reason is a lack of time, misunderstanding of the HIV mandatory declaration, or a technical problem (inability to connect to the application or to declare on paper, which requires the use of software to calculate the anonymity code).

Eight countries have established secure electronic data transfer systems dedicated to transferring laboratory data to the national surveillance system. Conversely, two rely on manual data entry into surveillance databases for data transmission while in four countries, data transfer occurs through automated interfaces between laboratories and the surveillance system.

E-DO

The implementation of an electronic reporting system via the e-DO application was initially authorised by the CNIL in 2015 for HIV. Since 2022, the e-DO platform has also been used for tuberculosis notifications. Biologists and doctors who diagnose and/or manage cases of HIV infection and AIDS are the users of the e-DO application, although other health professionals, such as medical or biology interns, as well as non-health professional staff, such as clinical study technicians (TEC) or medical secretaries, may also use the system and complete mandatory notification forms under the responsibility of the healthcare professional. The delegation of data entry to authorised persons was described by stakeholders as difficult, with challenges in account creation and system settings.

Since 2016, users of the e-DO system have faced several technical issues, including understanding the new system, ordering and renewing Cartes de Professionnels de Sante (CPS) and Carte de Personnel d'Etablissement (CPE) cards, equipping card readers, ensuring hospital computer system compatibility with the CPx23 card reader, and accessing the e-DO.fr site via compatible browsers.

Technical problems have persisted for years and have discouraged some users. Although some issues had been resolved by 2023, some centres still struggled to connect to e-DO and did not report HIV cases, although paper declarations were still possible. Adaptations to this limitation included designating specific doctors to manage data entry or ordering CPE cards limiting the number of computers for e-DO access. Recurrent difficulties included software updates affecting CPx (ie CPS and/or CPE) cards, inconsistent card ordering and renewal processes, and a lack of sufficient IT support for e-DO connections. Understanding and creating e-DO accounts also posed challenges.

Distrust and doubts from stakeholders can be amplified by the limits, initially imposed by the CNIL, on the data extracted from the e-DO tool and on data that Santé publique France can share with COREHIV or other stakeholders.

Data management

Twenty-two countries, including France, reported having structured data management procedures in place, which included data validation and secure storage within databases. Table 6 below describes the process employed to validate data provided by clinicians and/or laboratories used by EU/EEA countries. France conducts most of the validation activities outlined in the table below.

Table 6. Processes employed to validate data provided by clinicians and/or laboratories by countries

Country	Data collection	Data cleaning	Data verification	Quality assurance	Documentation	Continuous monitoring
Austria						
Belgium						
Croatia						
Cyprus						
Czechia						
Denmark						
Estonia						
Finland						
France						
Germany						
Greece						
Ireland						
Italy						
Liechtenstein						
Luxembourg						
Malta						
Netherlands						
Norway						
Portugal						
Romania						
Spain						
Sweden						

Note: Lithuania and Slovenia did not reply to this question
Data collection: Gathering HIV-related information from various sources such as healthcare facilities, laboratories, and community outreach programs.
Data cleaning: Reviewing the collected data to identify and correct errors, inconsistencies, and missing entries.
Data verification: Confirming the accuracy of the data by cross-referencing with other reliable sources or employing validation techniques.
Quality assurance: Implementing measures to ensure data quality and reliability throughout the validation process.
Documentation: Thoroughly documenting the validation process, including any discrepancies and steps taken to address them, for transparency and accountability
Continuous monitoring: Continuously monitoring and assessing the surveillance system to identify areas for improvement and ensure ongoing data quality assurance
The data in this table for countries other than France are provisional. Therefore, slight changes in the data displayed for those countries could occur when the full report from the Survey of EU/EEA HIV surveillance focal points is published.

Countries face numerous challenges in data analysis, including limited variables, time constraints, and understaffing. Insufficient epidemiological data requires manual extraction, compromising data integrity in some countries, whereas in others, fragmented healthcare systems and data protection regulations further complicate analysis. Shortfalls in resources and personnel exacerbate these challenges, particularly in accessing complete clinical datasets.

Various unique identifiers, including social health insurance numbers, pseudonymised national register numbers, personal identification numbers (OIB), IDs, names, CPR numbers, and social security numbers, are used in HIV surveillance systems. Patient-specific data such as names, dates of birth, and specimen IDs are also employed. In some countries, alphanumeric HIV codes are being transitioned to electronic systems. For instance, in one country, identification methods may vary regionally, including with ID numbers and date of diagnosis, and could also be free text. In 11 countries, the identifier utilised in surveillance systems can be employed to trace back to personal information from other sources. Conversely, in 10 countries, including France, linking back with other sources of information using the identifier is not feasible. Out of the 24 countries surveyed, 20, including France, have the capability to identify and eliminate duplicates within their surveillance systems.

Stakeholder interviews indicated that the investigation of cluster transmission is hindered because there is no national database and because data cannot routinely be linked with other datasets, as sequences cannot be linked with patient identification numbers (ie, the DO). The data are anonymised, making it impossible to link back to individual patients.

Stakeholders also raised issues about the legal considerations regarding the anonymisation of data and the extent to which Santé publique France can engage with patients and clinicians for further response. This is a delicate matter as data must remain anonymous in accordance with notification laws. While ARS have the authority to investigate cluster outbreaks and decide on partner notification, the procedures for this process are currently unclear under existing laws.

Data quality

Table 7 summarises the results of the data quality of the HIV surveillance system obtained from the benchmarking between France and the other 23 EU/EEA countries.

Table 7. Summary of data quality of the HIV surveillance system: benchmarking between France and 23 EU/EEA countries

*	Data quality	France	EU/EEA (23 countries)
	Completeness of key surveillance variables reported to TESSy	Variable completeness for 2022 diagnoses: age and gender (100%), transmission (65.8%), CD4 cell count at diagnosis (57.4%), country of birth (76.7%), HIV status (74.7%), which is the variable that identifies cases previously diagnosed with HIV	Higher than the EU/EEA average for gender and age; Lower than the EU/EEA average for transmission, CD4 count at diagnosis, country/region of birth

** Yellow=some deviations or areas where closer examination may lead to improvements.*

Data quality focuses on the completeness of key variables reported as part of HIV surveillance and reported to the European HIV Surveillance System (TESSy).

Data are reported by France to TESSy by July each year and includes data for the prior year. Data completeness for key variables for adequate epidemiological analysis are detailed in Table 8. France has higher completeness than the EU/EEA average for gender and age, and lower than the EU/EEA average for transmission, CD4 count at diagnosis, and country/region of birth.

Table 8. Completeness of TESSy data by variable, France and EU/EEA average, 2022

Variable	France (%)	EU/EEA average (min-max) (%)
Age	100	99.6 (88.8-100)
Gender	100	99.1 (91.5-100)
Transmission	65.8	72.7 (21.2-100)
CD4 cell count at diagnosis	57.4	68.2 (6.0-100)
Country of birth/region of origin	76.7	87.1 (51.8-100)
HIV status	74.7	51.4 (0-100)

Source: ECDC/WHO HIV/AIDS surveillance in Europe 2023 (2022 data) [3].
**Red=major issues noted as compared to other EU/EEA countries and European surveillance standard; Green=areas where the system is performing well and in line with or above the EU/EEA average*

Stakeholders commented on and were concerned by low completeness for variable transmission, country of birth and CD4 cell count and were concerned that this was more challenging since the COVID-19 pandemic. The role of the COREVIHs, particularly the technicians (TECs) and other regional actors on improving the completeness of key

epidemiological variables was seen as holding great potential to improve data quality. This has already been enacted in some regions with good results but would be much easier, according to several stakeholders, if TECs were given an official role as part of the DO reporting form process and data validation procedure. Additional ideas from stakeholder interviews to improve data quality were using automated data transfer in the reporting form from medical records, such as the NADIS system.

Nearly all stakeholders commented extensively on issues of under-reporting as part of the perception of the quality of the data produced as part of HIV surveillance in France, and this is covered in the report section 'Representativeness'.

Opinions on the usefulness of imputation to correct for missing data were mixed. Stakeholders in the research sector saw this as useful for modelling, although most other stakeholders were sceptical of adjustments to the data and felt that it undermined trust in the data and the work of Santé publique France.

Acceptability

Table 9 summarises the results of the acceptability attribute of the HIV surveillance system obtained from the benchmarking between France and the other 24 EU/EEA countries.

Table 9. Summary of the acceptability of the HIV surveillance system: benchmarking between France and 24 EU/EEA countries

*	Acceptability	France	EU/EEA (24 countries)
	Barriers to clinicians reporting HIV cases	Time constraints, inadequate reporting infrastructure, and complexity of reporting processes are listed as barriers.	Many EU/EEA countries also list time constraints (16/24), while some list inadequate reporting infrastructure (7/24), the complexity of reporting processes (4/24), and lack of training (5/24)
	Barriers to laboratories reporting HIV cases	Time constraints and complexity of reporting processes are listed as barriers.	Some EU/EEA countries also list time constraints (4/24) and complexity of reporting processes (3/24)

**Red=major issues noted as compared to other EU/EEA countries and European surveillance standard.*
The data in this table for countries other than France are provisional. Therefore, slight changes in the data displayed for those countries could occur when the full report from the Survey of EU/EEA HIV surveillance focal points is published.

Acceptability refers to the willingness of persons and organisations to participate in the surveillance system, and the degree to which each of these users is involved in surveillance [1]. This attribute is a critical function of an effective HIV surveillance system. To limit the under-reporting of a new HIV diagnosis and to identify the best ways to improve the current surveillance system, it is crucial to assess stakeholders' willingness to participate in this system.

Acceptability was not directly assessed in the survey, but questions were included on primary barriers to clinicians reporting newly diagnosed HIV cases to the surveillance system. These include time constraints (16 countries, including France), inadequate reporting infrastructure (seven countries, including France), followed by the complexity of the reporting process (four countries, including France) and lack of training (five countries). For countries where laboratories report newly-diagnosed HIV cases to the surveillance system, the reported barriers are time constraints (four countries, including France) and the complexity of the reporting process (three countries, including France).

Notably, France reported that both clinicians and laboratories face barriers to reporting, including time constraints, the complexity of the reporting process, and inadequate reporting infrastructure.

Stakeholders commented extensively on acceptability, indicating that changes due to 'test and treat' for HIV implemented in 2013 changed the dynamic and perceived motivation of actors from some laboratories and regional hospitals and clinics. Several stakeholders from laboratories and COREHIVs indicated that laboratories and clinicians outside of hospitals regard notification as the work of the university hospital where treatment starts, and thus many cases now 'fall between the cracks'.

Acceptability was also impacted by the very heavy workload amongst clinicians and laboratories, combined with a feeling that the data are input 'into a void without tangible outcomes'. The transmission of data to the central level, through a difficult-to-access and use e-DO interface, with little direct feedback regarding the regional picture, was seen as reducing acceptability and motivation. Stakeholders mentioned that dashboards, better or automated notification forms, and feedback on the data to allow it to be applied to regional prevention activities, would all improve acceptability.

Usefulness

Table 10 summarises the results of the usefulness of the data from the HIV surveillance system obtained from the benchmarking between France and the other 24 EU/EEA countries.

Table 10. Summary of the usefulness of the data from the HIV surveillance system: benchmarking between France and 24 EU/EEA countries

*		France	EU/EEA (24 countries)
Usefulness			
	Annual HIV continuum of care estimates	Last estimates are from 2018	All EU/EEA countries have more recent estimates
	HIV continuum of care estimates for key populations	No key population estimates for any stage of the HIV continuum of care are reported as part of Dublin declaration monitoring.	One or more stages were reported by other EU/EEA countries for: MSM=17 countries; PWID=15 countries; migrants=11 countries; sex workers=three countries; prisoners=eight countries
	Can identify and link AIDS cases occurring after HIV infection	Yes	Most EU/EEA countries can do this (20/24)
	Can identify previous positive cases	Yes	Most EU/EEA countries can do this (18/24)
	Can report on deaths among cases reported to the HIV surveillance system	Can report date of death but not cause of death	8/24 countries can report on date and cause of death while 7/24 can report only date of death

**Red=major issues noted as compared to other EU/EEA countries and European surveillance standard; Yellow=some deviations or areas where closer examination may lead to improvements; Green=areas where the system is performing well and in line with or above the EU/EEA average.*
The data in this table for countries other than France are provisional. Therefore, slight changes in the data displayed for those countries could occur when the full report from the Survey of EU/EEA HIV surveillance focal points is published.

Usefulness refers to the HIV surveillance system's capacity to provide valuable, relevant, and actionable information to support public health efforts in understanding, preventing, and managing HIV infections. A surveillance system's usefulness is determined by the usefulness of the data it generates in informing evidence-based decision-making and public health interventions. This attribute encompasses the system's ability to track trends, identify high-risk populations, monitor the impact of prevention and treatment programs, and contribute to the overall improvement of HIV-related outcomes. A utility-focused HIV surveillance system ensures that the data collected are not only accurate and timely but also serve the specific needs of policymakers, healthcare professionals, researchers, and other stakeholders involved in the prevention and control of HIV. This attribute emphasises the practical and meaningful application of surveillance data in guiding strategies and interventions to effectively address the HIV epidemic.

The majority of stakeholders indicated that the role of mandatory notification of AIDS or deaths could be revisited, unless occurring close in temporal proximity to the HIV diagnosis. Reasons for this were that this data are not being used to guide public health action and can be yielded from the HIV cohorts.

In this context, we explore the system's capacity to report on indicators to evaluate France's progress towards the implementation of the SNSS including the usefulness of epidemiological data, HIV trends in key risk groups, the HIV continuum of care and HIV incidence nationally and by region. Furthermore, we comment on the system's efficacy in identifying previous positive cases for individual analysis and the system's capability to incorporate AIDS data into the HIV surveillance system, facilitating the notification of AIDS cases after HIV notifications, and providing information related to mortality. Some of these factors are very linked to issues described in the sections on 'Representativeness', 'Timeliness' and 'Communication'.

Usefulness of epidemiological data produced by the surveillance system

Stakeholders interviewed had diverse needs for the epidemiological data produced by the HIV surveillance system, but there was broad agreement that essential needs include an annual description of epidemiological trends by sex and age and in key risk groups, including transmission mode and country of birth. Information on the stage of infection or CD4 count at diagnosis was seen as important. Some stakeholders indicated that data on numbers tested for HIV as well as data on co-infections was important for guiding programmes and contributing to SNSS indicators. Stakeholders want a national picture but also more information on the regional situation, produced in discussion with regional data generators and users to be adapted to local needs and epidemiology.

There was widespread dissatisfaction with and lack of understanding of the adjustments made to the data for under-reporting (see 'Representativeness') and this was seen as undermining the usefulness of the data produced, both due to the delays in data processing and the inability of data generators and users to recognise their local data. Many stakeholders from regional and COREVIH levels described using parallel systems of local data from the COREVIHs or cohort data submitted to NADIS to inform and evaluate their prevention activities, rather than relying on annual data produced by Santé publique France. The main reasons for this were due to the adjustments made

to the data as well as to the timeliness with which the data is produced and shared with the regions, which was thought to be too infrequent to inform local actions.

There was also concern that the data published did not capture local efforts regarding prevention, particularly in the area of the impact of PrEP on HIV incidence among men who have sex with men. Reasons for this were broadly thought to be related to the data validation timeline and due to adjustments made to the data.

Usefulness of HIV continuum of care indicators, including HIV incidence estimates

France stands out as the EU/EEA country that has the most outdated estimates for the HIV continuum of care indicators submitted to the HIV monitoring, dating back to 2018. All other EU/EEA countries have updated one or several of their 95-95-95 indicators more recently [4]. No data for any stage of the HIV continuum of care were reported by France for any of the key populations while one or more stages were reported by other EU/EEA countries for the following key populations: MSM=17 countries; PWID=15 countries; migrants=11 countries; sex workers=3 countries; prisoners=8 countries [4].

Interviews indicated that stakeholders were highly dissatisfied with the lack of updated estimates for HIV incidence as well as for the undiagnosed population (ie, the first 95 estimates) and needed this information to evaluate the progress of the SNSS and prevention interventions and to guide testing initiatives regionally and nationally. It was discussed and understood by many stakeholders that work to develop HIV estimates had been taken on by Santé publique France and this was seen as positive and a priority, although it was acknowledged that the work was challenging due to issues of under-reporting and missing data.

Stakeholders interviewed described that the result of the recent infection test may be used in the calculation of HIV incidence, however this has not been the case for several years and the introduction of pre-exposure prophylaxis for HIV (PrEP) has introduced complexities into accurately performing this calculation.

Usefulness of identification of previous positive cases, AIDS cases and mortality

In the review of TESSy data and European HIV surveillance reporting practices, France was able to identify and link HIV and AIDS cases occurring downstream after HIV infection. This is in line with the 20 EU/EEA countries identified in the survey as able to do this.

According to the country survey, eighteen countries, including France, can identify previous positive diagnoses. For mortality reporting, only eight countries can retrieve both the date and cause of death; seven can retrieve only the date of death (including France).

According to stakeholder interviews, the system's ability to identify previous positive cases was seen as highly useful and epidemiologically important, but the current presentation and analysis of data do not differentiate these cases adequately. Stakeholders mostly agreed that AIDS is no longer a significant public health concern and that the focus for surveillance should be on AIDS occurring at the time of HIV diagnosis, as an indication of late diagnosis. Other reasons for AIDS (treatment interruptions or failures) can adequately be captured by the HIV cohorts. Mortality statistics were seen as important, but those generated through the current surveillance system are not being used by any of the stakeholders and it was acknowledged that there are other sources for this data.

Simplicity

Table 11 summarises the results of the simplicity of the HIV surveillance system obtained from the benchmarking between France and the other 24 EU/EEA countries.

Table 11. Summary of the simplicity of the data from the HIV surveillance system: benchmarking between France and 24 EU/EEA countries

*	Simplicity	France	EU/EEA (24 countries)
	The ease and straightforwardness with which the HIV surveillance system can be understood, implemented, and maintained.	There is a centralised database with case notifications from clinicians and laboratory reports, though manual data. The low data linkage is due to underreporting by clinicians and/or biologists, resulting in approximately 51% to 75% of cases being linked. Once cases are reported by both biologists and clinicians, the data can be linked easily. Despite secure data transfer and management procedures, challenges include limited system interoperability, technical issues in data matching, and barriers faced by clinicians and laboratories in reporting.	France appears to face more challenges in this area than other EU/EEA countries

**Red=major issues noted as compared to other EU/EEA countries and European surveillance standard.*
The data in this table for countries other than France are provisional. Therefore, slight changes in the data displayed for those countries could occur when the full report from the Survey of EU/EEA HIV surveillance focal points is published.

Simplicity refers to the ease and straightforwardness with which the HIV surveillance system can be understood, implemented, and maintained. A simple HIV surveillance system is characterised by clear and uncomplicated processes, user-friendly interfaces, minimal complexity in data collection and reporting mechanisms, and ease of interpretation of surveillance results. Simplicity is a crucial aspect in ensuring that the surveillance system is accessible to various stakeholders, including healthcare professionals, data analysts, and policymakers, facilitating efficient and effective use of the system for monitoring and responding to the HIV epidemic.

The simplicity of France's HIV surveillance system is a central theme throughout this report. Notably, France has a case notification form for clinicians and biologists supported by a centralised database within its national surveillance system. When both clinician and laboratory reports exist, they can be linked (unless there are major issues with inputting data for the anonymity code). The problem lies in underreporting, which results in some laboratory reports lacking corresponding clinician reports. As a result, only about 51% to 75% of the laboratory data can be linked to the data reported by clinicians. Despite its streamlined approach, France faces several challenges, including a lack of interoperability between systems (HIV surveillance database and hospital databases) and resources for data integration. However, France has established secure electronic data transfer systems and structured data management procedures, encompassing data validation and secure storage within databases. Nevertheless, France cannot link back mandatory reports data with other sources of information using identifiers due to data protection constraints. Additionally, both clinicians and laboratories encounter barriers to reporting, including time constraints, reporting process complexity, and inadequate infrastructure.

Stakeholder interviews expressed broad concern with the complexity and lack of coordination of HIV surveillance at various levels.

The current mandatory reporting system (HIV infection and AIDS) lacks flexibility and data flow is not smooth from the healthcare providers in laboratories and hospitals to the regional and national levels.

The e-DO interface for reporting was seen as highly outdated and problematic, and the system for reporting, querying and validation of data was seen as inefficient (see 'Tools and technical resources' section). The system was described as not using modern approaches to capture data, such as automated interfaces from health records or laboratory batch reporting, as well as not capitalising on the potential of systems like LABOé-SI or SNDS. The system was seen as lacking flexibility and not being adapted to the reality of modern HIV testing, treatment or care.

The process of adjusting data for under-reporting by using LaboVIH was described as complex and non-transparent.

Representativeness

Table 12 summarises the results of the representativeness of the HIV surveillance system obtained from the benchmarking between France and the other 24 EU/EEA countries.

Table 12. Summary of the representativeness of the data form the HIV surveillance system: benchmarking between France and 24 EU/EEA countries

*		France	EU/EEA (24 countries)
Representativeness			
	Geographical coverage	100%	21/24 EU/EEA countries report 100% coverage
	Under-reporting in general and by clinicians	Estimated at 43% in general, 56% among clinicians	France is among the countries with the highest overall underreporting in the EU/EEA
	Under-reporting by laboratories	52%	8% average of the 16 countries that also reported that laboratories report
	Use of any method to estimate the extent of underreporting	Yes	Only 8/24 countries have a method in place to assess the level of underreporting
	Can identify key populations for HIV prevention	Yes (captures data on MSM, PWID, people born abroad, and transgender people)	Most EU/EEA countries' reporting systems capture data on MSM, PWID, people born abroad. 10/24 countries capture data on transgender people

**Red=major issues noted as compared to other EU/EEA countries and European surveillance standard; Green=areas where the system is performing well and in line with or above the EU/EEA average*
The data in this table for countries other than France are provisional. Therefore, slight changes in the data displayed for those countries could occur when the full report from the Survey of EU/EEA HIV surveillance focal points is published.

Representativeness is the extent to which the features of the population of interest are reflected by the population included in the surveillance activity. These features may include geographical location or inclusion of key populations.

Regarding the coverage of the HIV surveillance system, 21/24 countries, including France, reported 100% geographical coverage.

Sixteen countries reported that laboratories also contribute to the HIV surveillance system, including France. Notably, France is among the countries with the highest overall underreporting, ranking in the first quartile along with Germany, Spain, Estonia, and Austria. Despite most countries in the survey acknowledging the existence of underreporting, 13 countries indicated that they do not conduct any assessment or estimation of under-reporting through any method. Consequently, the figures they provide are based solely on conjecture. In contrast, three countries (Denmark, Finland, and Germany) estimate the level of underreporting through statistical modelling and extrapolation based on known cases and surveillance data. Romania bases its estimation on analysing trends in healthcare-seeking behaviour and comparing them with reported case counts, while Czechia, Estonia, France, and the Netherlands use other methods. France indicated that the underreporting estimation was conducted in 2022.

France's surveillance infrastructure can identify MSM, people who inject drugs, transgender people, and people born abroad, encompassing the majority of important key populations targeted for HIV prevention interventions.

In stakeholder interviews, there was widespread agreement that the right key population groups and indicators are included in and reported on within the HIV surveillance system, however, issues raised were around the validity of the data reported due to corrections for under-reporting and imputation of missing data. Almost none of the stakeholders understood or believed in the approach for the adjustment for under-reporting and this was described as undermining their overall belief in the data and raising questions about its representativeness. This was particularly the case for some regions, including overseas territories where the epidemiology of HIV has different dynamics.

Timeliness

Table 13 summarises the results of the timeliness of the HIV surveillance system, as described in this section, obtained from the benchmarking between France and the other 24 EU/EEA countries.

Table 13. Summary of the timeliness of the HIV surveillance system: benchmarking between France and 24 EU/EEA countries

*	Timeliness	France	EU/EEA (24 countries)
	Guidelines to specify the maximum timeframe to notify HIV cases	No	11/24 EU/EEA countries have standards for the maximum transmission time of results
	Current notification time from diagnosis to report to the national system	100 days	EU/EEA average =137 days (range 0-999)

** Yellow=some deviations or areas where closer examination may lead to improvements*
The data in this table for countries other than France are provisional. Therefore, slight changes in the data displayed for those countries could occur when the full report from the Survey of EU/EEA HIV surveillance focal points is published.

Timeliness is usually defined as the time between any two defined steps in a surveillance system. The time points chosen are likely to vary depending on the purpose of the surveillance activity.

In terms of timeliness, the survey measured the duration that clinicians take to report results to the national surveillance system. In this regard, Table 14 compares by country the availability of guideline-defined transmission time and current notification time for clinicians reporting cases to the national surveillance system. It shows that only 11 countries reported having existing guidelines specifying a standard timeframe for the maximum transmission time of results. Conversely, eight countries, including France, do not have this standardised timeframe defined in any document. Notably, among the countries that reported a timeframe for notification, there were no delays observed in reporting from clinicians.

Table 14. Comparison availability of guideline-defined transmission time and current notification time for clinicians reporting cases to the national surveillance system by country

	Guideline-defined transmission time(days)	Current notification time (days)
Austria	-	-
Belgium	-	-
Croatia	-	180
Cyprus	15	5
Czechia	-	-
Denmark	-	60
Estonia	1	-
Finland	7	-
France	**-**	**100**
Germany	-	30
Greece	-	0
Ireland	-	-
Italy	150	45
Liechtenstein	7	-
Lithuania	-	-
Luxembourg	-	999
Malta	-	30
Netherlands	-	-
Norway	-	-
Portugal	1	122
Romania	10	30
Slovenia		-
Spain	365	180
Sweden	1.5	2
14 EU/EEA Median	**62 (range: 1-365)**	**137 days (range: 0-999)**

The data in this table for countries other than France are provisional. Therefore, slight changes in the data displayed for those countries could occur when the full report from the Survey of EU/EEA HIV surveillance focal points is published.

In stakeholder interviews, it was highlighted that the time required for analysing data and communicating results to stakeholders is a significant issue. Specifically, the reporting of HIV/AIDS and the capture of other parameters for a mathematical model that provides reliable estimates of HIV incidence and the first 95 target lack timeliness.

There has been no full update since 2018. Stakeholders agreed that such an update would be needed annually at the national level, with estimates for key populations and for regions where HIV is concentrated also provided periodically.

One of the issues regarding timeliness is the lack of time for data validation, addressing queries, and amending discrepancies. Data are released upon publication without allowing those who provide the data sufficient time to validate and agree with what will be published for World AIDS Day. This challenge is even more pronounced for the overseas regions.

The timeliness of the epidemiological data reported annually for Worlds AIDS Day was also seen as lacking by stakeholders. While annual reporting was broadly seen as acceptable, the current lag from when data are reported until they become publicly analysed and available to guide public health and prevention action was viewed as problematic. Reporting data from the year prior for World AIDS Day the following December was viewed as too late to meet partners' needs, particularly in the context of evaluating progress towards the SNSS and progress towards meeting 2030 targets.

It was suggested by stakeholders to simplify objectives and the process of data validation and adjustments to improve timeliness. Many stakeholders acknowledged that the Santé publique France HIV team is overstretched and has had a substantial focus on trying to increase data quality, causing a high workload and significant stress. It was suggested that Santé publique France could produce data without adjustments in a timelier manner and in collaboration and discussion with data providers and stakeholders.

Communication

Table 15 summarises the results of the communication methods of the HIV surveillance system, as described in this section, obtained from the benchmarking between France and the other 24 EU/EEA countries.

Table 15. Summary of the communication methods of the HIV surveillance system: benchmarking between France and 24 EU/EEA countries

*	Communication methods	France	EU/EEA (24 countries)
	Frequency of communication of surveillance results	Annually	15/24 countries communicate annually; 2/24 biannually; 1/24 quarterly; 2/24 monthly
	Methods of communication	Epi bulletins, scientific articles, website	Most countries use a variety of methods including epi bulletins, scientific articles, website; some countries also use dashboards (7/24) and social media (8/24)

** Yellow=some deviations or areas where closer examination may lead to improvements.*
The data in this table for countries other than France are provisional. Therefore, slight changes in the data displayed for those countries could occur when the full report from the Survey of EU/EEA HIV surveillance focal points is published.

Outputs

Twenty countries regularly publish reports and/or scientific articles on surveillance results released by their respective surveillance systems. Fifteen countries, including France, report their results annually, while two release reports every six months, one quarterly and two provide monthly updates on surveillance findings.

Similar to other EU/EEA countries, France focuses its communication efforts on targeting the general public, network members, clinicians, private and public national partners, civil society, politicians, researchers, and key populations.

Table 16 describes the various methods used by countries to communicate surveillance results, showing that the most used means include websites (21 countries) and epidemiological bulletins or reports (19 countries), followed by scientific articles (14 countries), social media (eight countries), and dashboards (seven countries). France employs epidemiological national and regional bulletins or reports, scientific articles, and websites to disseminate its results.

Table 16. Methods used by countries to communicate surveillance results

Country	Dashboards	Epi bulletins or reports	Scientific articles	Social media	Website	Other
Austria		■	■		■	
Belgium	■	■	■		■	
Croatia		■	■		■	
Cyprus						■
Czechia		■	■		■	
Denmark	■	■	■		■	
Estonia	■	■	■	■	■	
Finland	■	■			■	
France		■	■		■	
Germany		■	■	■	■	
Greece		■			■	
Ireland	■	■	■	■	■	
Italy		■	■	■	■	
Liechtenstein		■	■		■	
Luxembourg		■			■	
Malta					■	
Netherlands	■	■	■	■	■	■
Norway	■	■	■	■	■	
Portugal		■		■	■	
Romania					■	
Spain		■	■		■	
Sweden		■		■	■	

Note: Lithuania and Slovenia did not reply to this question
The data in this table for countries other than France are provisional. Therefore, slight changes in the data displayed for those countries could occur when the full report from the Survey of EU/EEA HIV surveillance focal points is published.

Stakeholder interviews revealed that the annual report does not fully meet stakeholder needs, as many of the stakeholders from the regions indicated that they would appreciate more detailed regional data, especially concerning key populations. One issue discussed was the lack of a dedicated space for discussion and review to extract more insights from the data. Ideally, feedback should occur annually, with interim alerts provided more frequently to flag emerging issues, rather than waiting until November for the annual report. It was highlighted that there is an existing law governing the publication of public data, mandating Santé publique France to publish data and assume responsibility for its dissemination.

It was suggested that a dashboard could be an ideal tool for sharing data promptly with the prevention sector and fostering closer collaboration.

Communication from Santé publique France to stakeholders

Many stakeholders interviewed commonly commented that, to date, there has been little feedback provided to the 'true' reporters (i.e. the clinical technicians) and they believe that providing information back to those who are reporting at the service level and the COREVIH level will enhance their interest and motivation to ensure the exhaustiveness and completeness of their notifications. Furthermore, it was emphasised that there is a general need to rethink the entire communication strategy between Santé publique France and reporters, engaging them in actions of mandatory reporting as a public health rather than an administrative action.

Communication is primarily top-down from Santé publique France to those who are reporting and focuses on the technical management of the system rather than on the co-production of data that are useful to all stakeholders.

To increase support and commitment from the professionals involved, the communication between Santé publique France and all those engaged in reporting activities needs to be restructured. The focus should be on coordinating the network of reporters, fostering regular dialogue, and recognising their contributions. To further harmonise reporting practices, instructions to reporters need to be clear, understood, and shared. Additionally, it is necessary to organise regular feedback sessions for reporters on their activities and the data produced from these activities.

Communication within COREVIHs

It was mentioned during the interviews, that communication between COREVIHs to share procedures and strategies exists but is not extensive. Yearly meetings of COREVIH representatives, known as the Groupe d'Interface National (GIN), are organised by the DGS. The Société Française de Lutte contre le Sida (SFLS) is a multidisciplinary scientific society that brings together all stakeholders in the fight against HIV/AIDS in France. It provides a forum for COREVIH members to meet more extensively at an annual conference and in dedicated workshops.

Communication and coordination of all HIV-related stakeholders

It was discussed during the interviews that the Ministry of Health (DGS) does not directly coordinate the overall system. Santé publique France, INSERM and ANRS are at times viewed as operating in silos. Consequently, there is a notable gap in leadership and continuity in steering HIV control efforts which was seen as necessary from the level of the Ministry of Health to coordinate more strongly. This gap is largely due to the lack of reliable and relevant data needed to inform stakeholders at local, regional, and national levels. The data needs for the SNSS were viewed as those that should steer the data production and interpretation by all actors in a coordinated manner.

Evaluation processes

Table 17 summarises the results of the evaluation processes of the HIV surveillance system obtained from the benchmarking between France and the other 24 EU/EEA countries.

Table 17. Summary of the evaluation processes of the HIV surveillance system: benchmarking between France and 24 EU/EEA countries

*	Evaluation processes	France	EU/EEA (24 countries)
	Internal evaluation conducted	Yes, in 2019	Seven EU/EEA countries, including France have conducted an internal evaluation.
	External evaluation conducted	Present evaluation	Five EU/EEA countries, including France have conducted/are conducting an external evaluation.

** Green=areas where the system is performing well and in line with or above the EU/EEA average.*
The data in this table for countries other than France are provisional. Therefore, slight changes in the data displayed for those countries could occur when the full report from the Survey of EU/EEA HIV surveillance focal points is published.

Internal evaluation

Seven EU/EEA countries, including France, have conducted an internal evaluation. The methods employed vary, but they are primarily based on ECDC guidelines, and were carried out between 2015 and 2024, encompassing various surveillance attributes. France's internal evaluation was carried out in 2019, and the findings fed into the request for and results of the present assessment.

External evaluation

External evaluations have been conducted by five EU/EEA countries, including the present assessment being undertaken for France. These evaluations covered various attributes, including usefulness, acceptability, representativeness, flexibility, sensitivity, timeliness, data collection, use of data, internal management, timeliness, data completeness, simplicity, flexibility, acceptability, and stability.

Stakeholders viewed the engagement of Santé publique France in the present external evaluation as very positive and were interested to participate and share their views, with many anticipating that their views would be considered by Santé publique France.

Overall considerations

The main objectives of HIV surveillance in France are to efficiently estimate the number of new HIV diagnoses and then to carry out annual estimates of other key indicators (e.g. HIV incidence, continuum of care). Although the need to update these objectives was outlined during the evaluation, they remain relevant to guide the system's performance and to monitor, evaluate and inform HIV prevention and care services in France, as well as the SNSS. It was evident from this review that the surveillance systems' objectives are not being fully met.

Notification of HIV and the data yielded from HIV surveillance remain crucial and indispensable. However, the role of data collection and the need for strategic HIV data have evolved, and the current system is not keeping pace. Most stakeholders indicated that the role of mandatory HIV notification remains vital, reinforcing the need for an updated and efficient data collection system. To effectively combat the epidemic, data must be both national and regional, providing key information to guide strategies, focusing on trends, key populations, and the undiagnosed population.

What is working well

The HIV surveillance system was described by all stakeholders as highly valued. Stakeholders consider the data provided by the system are crucial for measuring and guiding the HIV response. Useful indicators are collected by the system and these will be increasingly beneficial if produced in a more transparent and timely manner, accompanied by more dialogue and engagement with stakeholders.

Stakeholders appreciate the work of Santé publique France, largely understand the system's complexity, and are actively engaged with it and its demands. There appears to be broad support for the SNSS strategy which provides a clear roadmap for actions and a helpful framework for the data needs that the HIV surveillance system should fill.

France is fortunate to have an array of very rich data sources, highly skilled experts, and many stakeholders that are interested and engaged in the field of HIV. The COREVIH system and the HIV cohorts including FHDH database, along with the SNDS insurance system and the potential for inclusion of HIV in the LABOé-SI are unique assets that France can exploit more to help support and complement HIV surveillance and other strategic HIV data information needs.

Technicians hired by the Ministry of Health as part of the COREVIHs are an excellent existing asset that could be utilised further to support and improve the work of HIV surveillance.

France is among the few countries that have performed both internal and external evaluations to assess the system's performance. Notably, France is one of the eight countries in the EU/EEA that assesses underreporting and data on the percentage of underreporting by clinicians and laboratories.

Recruitment of a modeller to the Santé publique France team, who is prioritising and making good progress on the work of data adjustments, HIV incidence and PLHIV estimates is a very positive development.

Challenges identified

The objectives of HIV surveillance are not aligned with the current context and information needs, and the reporting protocol is outdated. Although France has formalised its HIV surveillance system, it lacks a comprehensive document detailing the roles of all partners within the network, and there is no steering committee in place to set objectives for the surveillance network and to make strategic decisions.

Despite substantial resources and efforts invested in the system, it does not currently provide the data needed by stakeholders in a timely manner and there is a lack of trust in the results yielded. Issues were raised about the validity of the data reported due to corrections for underreporting and imputation of missing data. Underreporting in France is among the highest compared to other countries in Europe. Almost none of the stakeholders understood or believed in the approach for adjusting for underreporting, undermining their overall confidence in the data and raising questions about its representativeness. This issue is particularly pronounced in some regions, including overseas territories where the epidemiology of HIV has different dynamics.

The data collected are not timely enough to inform action. There have been no updated estimates of HIV incidence, time from infection to diagnosis, and the undiagnosed population of people living with HIV since 2018. Stakeholders, especially in regions, feel disconnected from the processes at Santé publique France and the produced data. There is a significant unmet need for two-way dialogue about data completeness, flow, and results.

The perceived lack of reliable data and insufficient involvement of regional and clinical actors in data discussions result in reduced local ownership and use of data for action in regional settings. Stronger national coordination is needed among the many actors generating and using the data, potentially involving the Ministry of Health. The COREVIH system and regional actors are valuable assets for HIV surveillance but are underused. The Ministry of Health (DGS) could better coordinate the system including the priorities and actions of Santé publique France, ANRS, and INSERM.

Some indicators collected by the system are not used or duplicate other data sources (AIDS, death surveillance, recency testing). HIV surveillance in France does not currently take full advantage of complementary data sources such as cohorts, SNDS, and ARV prescription data.

The e-DO system is not functioning appropriately and appears nearly obsolete, requiring significant modifications that are not easily implemented. The card system for signing into the e-DO poses a barrier for clinicians and some laboratories, hindering easy reporting. Additionally, some data collected on the e-DO are unused, while other adaptations could be beneficial. Furthermore, the current e-DO platform has several issues complying with data protection law requirements, making urgent changes or improvements essential. Additionally, the e-DO system lacks interoperability, such as linking back to other information sources using a unique identifier. In France, reporting from laboratories and clinicians requires manual entry by declarants. Clinicians and biologists often lack clarity on what constitutes a new diagnosis and need better guidance and training within the mandatory notification system.

There is an imbalance between the Santé publique France HIV team's staffing levels and their workload.

Suggestions for improvement

Several areas for improvement were identified as part of this review, for consideration by the Ministry of Health, Santé publique France and other actors within the system.

- **The coordination mechanism for HIV data by the Ministry of Health should be strengthened**. France is fortunate to have an excellent array of data to inform the epidemiological situation for HIV, but they are not coordinated efficiently to maximise their benefit to public health and the SNSS. The role of strengthening the mechanism for coordination and the integration of all strategic information needs for HIV data lies with the Ministry of Health. Enhanced strategic coordination by the Ministry of Health of the inputs from Santé publique France, the COREHIVs, and other actors will improve understanding of key data needs and gaps. This approach will also guide data generation and promote the analysis and integration of data from the mandatory HIV notification system with complementary data sources such as HIV cohort data, SNDS, prescription data, and testing data to provide a more complete picture of the HIV situation in France. National coordination can be translated into regional data partnerships and synergies via the COREHIVs. This approach would make better use of the available resources and minimise overlap. This action should be enhanced immediately as it is fundamental to the optimal functioning of the system and other recommendations made here.
- **Santé publique France should focus considerably more time and effort on HIV stakeholder communication and engagement.** Stakeholders unanimously expressed a desire for substantially more opportunities for two-way discussion and dialogue about reporting processes and about HIV surveillance data. Santé publique France should review processes to allow for more frequent stakeholder engagement and contact, possibly through a stakeholder engagement plan and through the use of local actors and technologies to engage more effectively and more frequently. This will boost the engagement and motivation of data reporters and, in the longer term, data quality and usefulness. Possible ideas for doing this could include dashboards to see and query the local data, monthly alerts, a dedicated space for discussion and review to extract more insights from the data. This action should be enhanced immediately.
- **The Ministry of Health and Santé publique France should prioritise improvements to the e-DO system**. The e-DO system is not functioning well and has security issues. For mandatory HIV notification to continue, this system must be majorly updated or rebuilt, allowing better functionality and interoperability with electronic health records and laboratory systems. Necessary legal and technical actions to enable HIV reporting to occur more efficiently should be explored, including the formal delegation of mandatory reporting actions to TECs and the possibility of using more efficient interfaces for delegated data queries and reminders, batch data notification via laboratory systems, including eventually the LABOé-SI system, as well as through interfaces with hospital health records such as NADIS. The interface for authentication should be simpler, such as through the e-CPS, and reporting should be available via the reporting portal so that declarants have one point of entry. Any changes in the system should enable some level of integration with the data from the old system to prevent data loss, particularly for the last decade, to allow the possibility for robust epidemiological analysis, including modelling of HIV incidence. Greater shared ownership for mandatory reporting would be enhanced if the revised system allowed professionals responsible for surveillance at a regional level to have a transversal vision of the data production and quality of the mandatory notification to enable. This action should be prioritised for resources and enacted as soon as possible.
- **The role of the COREVIH and other regional actors in mandatory reporting, improving data quality and collating regional data should be enhanced.** There are substantial resources already in place in the COREHIVs, with additional support available via ARS and Santé publique France regional staff. The COREHIVs could have a clearer mandate to improve reporting and data completeness, using the role of the TEC to support this. For this to be successful, COREHIVs would need clear direction from the Ministry of Health and ARS and would need to expand work in some regions to include contact with community hospitals and clinics as well as the university hospitals where COREHIVs tend to be based. Greater involvement of the COREVIHs and regional authorities would give more responsibility to the regions for data improvement and would allow regional data to be available in a timelier manner to drive local public health and prevention efforts. Good examples of this are already in place in some COREHIVs and these could be expanded to other areas, with clear oversight by the Ministry of Health to ensure coordinated standards for action across regions so that inequalities in reporting are not exacerbated. Such an approach would require attention to data governance and stewardship, with clear communication mechanisms in place among all actors and a clarified role for Santé publique France to coordinate, quality assure and collate data to enable national data and estimates.
- **The objectives for HIV surveillance should be reviewed and updated by Santé publique France, which should, in turn, guide updates to the type of data that is collected and how it is communicated.** The current objectives are not fully in line with the current needs of the system and should be updated, in communication and discussion with stakeholders who provide and use the data. The

framework of the SNSS and of global reporting requirements can provide a useful framework for the surveillance objectives update. Based on the updated objectives:

  - **The types of data collected as part of HIV surveillance should be reviewed.** The data collected on AIDS and deaths does not appear to be highly useful in the current context and is available from other sources. The system for recency testing is no longer used for HIV estimations and this could be discontinued in its current form. LaboVIH in its current form is not an efficient way to gather information on the number of people tested for HIV and could be replaced by batch reporting from laboratory systems or by LABOé-SI.
  - **The mandatory declaration form for HIV should be updated and simplified**, removing variables that are not used, not needed for surveillance purposes, or are available via other sources, such as the HIV cohorts, with the possible addition of variables relevant to the current context, such as clarification of the PrEP variable.
  - Once the mandatory notification form is updated, Santé publique France should coordinate **training and capacity-building workshops** to ensure that all actors are aware of what and how to report as part of the mandatory notification system, clarifying, in particular, the situation around the reporting of individuals previously known to be HIV positive.
  - **Revise the manner and timeliness with which the data are communicated to different types of stakeholders**, based on their needs.

- Santé publique France should continue to **prioritise work to generate estimates of HIV incidence, time from infection to diagnosis and the undiagnosed population**. This work has started in a positive manner and should be continued, with a focus on early presentation of results and continuous dialogue with stakeholders around the data and results. The new model should be made available and annual incidence estimates (overall and, where possible for key populations) should be produced.
- **Santé publique France should discontinue the current approach to adjustments of data for under-reporting.** The Labovih survey has been an increasingly inefficient mechanism to adjust HIV data for under-reporting and the current approach appears to undermine confidence in the data and to cause delays in the production of annual data, as the majority of stakeholders using the data found these adjustments confusing and unnecessary. If a substantially less resource-intensive method to adjust the data could be identified, this would also be an alternative worth exploring. The use of LABOé-SI for HIV is a good alternative to LaboVIH, but the timeline for its implementation is not clear. Given that stakeholders do not appear to find these adjustments essential, Santé publique France should consider discontinuing presenting adjusted data completely, focusing more on the key actions of stakeholder engagement, communication and support to regions to improve data quality.
- **Changes to the HIV surveillance system should be 'future proof' and utilise approaches to simplify and capture existing data more efficiently.** The LABOé-SI system provides possibilities for simplification of the laboratory notification of HIV cases in the future and this approach for HIV should be prioritised as soon as possible. The system should accommodate easier data extraction from electronic clinical and laboratory systems. Enhanced use of SNDS data should be used to replace or triangulate data currently collected through less efficient systems, and this could be explored by validating the SNDS data on a known cohort.

Limitations and interdependencies

There are several limitations to the approach taken in this evaluation which should be considered when interpreting its results and recommendations. The French system is complex and there was limited time to engage with all stakeholders or in an extensive manner within the scope of this evaluation, which led to simplification of the description of the issues or recommendations in some areas. The survey relied on self-assessment, and countries across the EU/EEA may have interpreted or considered questions differently. Furthermore, systems across the EU/EEA and the epidemiology of HIV differ substantially, making direct benchmarking challenging in some areas.

Ongoing evaluations of the COREHIV mandate and the HIV cohorts will influence the recommendations suggested in this report substantially and should be considered so that the next steps for the French HIV surveillance system are considered and undertaken in a coordinated and efficient manner, making the best use of the rich sources available to guide HIV surveillance, prevention and treatment programmes in France.

Acknowledgments

We would like to acknowledge Santé publique France for their openness, support and collaboration in facilitating contact with all the stakeholders who provided valuable insights for drafting this report. Their provision of documents and precise information was essential to understanding the current situation of the HIV surveillance system in France. We also appreciate their kindness and hospitality in Paris.

Additionally, we extend our thanks to all the stakeholders who took the time to share their valuable insights and knowledge about the HIV surveillance system. The ECDC team acknowledges the excellent contributions throughout the review from evaluation team members Viviane Bremer and Jean-Michel Thiolet. Despite the collective effort to gather information, the information and recommendations provided are issued under the full responsibility of the ECDC team.

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Annex 2. Programme for the country visit

12 March 2024

10:00-13:00	Santé publique France HIV Team
13:00-14:00	Lunch
14:00-15:30	Santé publique France Data Protection Officer
15:30-16:00	Break
16:00-17:30	Santé publique France Sexual health and prevention team

13 March 2024

10:00-12:00	Ministry of Health/ Direction Générale de la Santé
12:00-15:00	Lunch, transportation and mission team discussion
15:00-16:30	ANRS
17:30-18:30	Santé publique France: Direction générale et Direction des maladies infectieuses

14 March 2024

10:00-12:00	Conseil national du sida et des hépatites virales (CNS)
12:00-13:00	Lunch
13:00-14:30	AIDES
16:00-17:00	Cellules regionales
17:30-18:30	Initial feedback with Santé publique France

Annex 3. List of stakeholders interviewed

Name	Affiliation
François DABIS	Président du Copil de la stratégie nationale de santé sexuelle COREVIH Nouvelle Aquitaine
Rosemary DRAY-SPIRA	EPI-PHARE
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Annex 4. HIV surveillance system mapping

Annex Table 1. Summary of the organisational and functional attributes of the HIV surveillance system: benchmarking between France and 23 EU/EEA countries

*		France	EU/EEA (24 countries)
Surveillance system characteristics and objectives			
	Up-to-date surveillance objectives	Surveillance objectives are self-assessed as not up-to-date or in concordance with current context and needs for information	All but three EU/EEA countries self-assess their surveillance objectives as in accordance with the current context and needs for information, although some denote minor deficiencies. France along with two other countries report major deficiencies
	Steering committee in place	No committee in place	11/24 EU/EEA countries report having surveillance steering committee in place
	Up-to-date surveillance protocols in place and	Surveillance protocol in place but not up-to-date	12/16 EU/EEA countries with protocols in place report that the protocol is up-to-date
	Number of staff working in the HIV surveillance system	0.09 per one million population	EU/EEA average= 5.7 per million population
	Adequate human resources for HIV surveillance	Self-assessed as insufficient	About 1/3 of EU/EEA countries (7/22) report that resources are insufficient
	Financial resources for centralised team and database management	Self-assessed as insufficient and severely limiting surveillance activities	No other EU/EEA country reports major financial inadequacies for both the centralised team and database management that severely limit surveillance activities
Tools and technical resources			
	Database access and/or dashboard available to assist clinicians and laboratories in managing the data effectively	Clinicians and biologists have to enter their reports manually in e-DO. There is an e-DO dashboard however it is purely an informational tool and does not assist clinicians and biologists in managing their reports. It only shows the number of reports (not the number of people diagnosed)	11/24 responding EU/EEA countries enable database access for clinicians and laboratories reporting data. 4/22 have a dashboard for this purpose
	Percentage of laboratory data that can be linked with epidemiological data	51-75% (When both clinician and laboratory reports exist, they can be linked (unless there are major issues with inputting data for the anonymity code). The problem lies in underreporting, which results in some lab reports having no corresponding clinician report)	Most EU/EEA countries can link >75% of laboratory and epidemiological data
	Structured data management processes in place	Yes	22/24 EU/EEA countries have processes in place
	Can link to other sources of information based on personal identifier used to report HIV cases	No (limitation requested by the CNIL)	11/24 countries can link to information from other sources
	Can identify and eliminate duplicate cases	Yes	20/24 countries can identify and eliminate duplicates

*		France	EU/EEA (24 countries)
Data quality			
	Completeness of key surveillance variables reported to TESSy	Variable completeness for 2022 diagnoses: age and gender (100%), transmission (65.8%), CD4 cell count at diagnosis (57.4%), country of birth (76.7%), HIV status (74.7%), which is the variable that identifies cases previously diagnosed with HIV	Higher than the EU/EEA average for gender and age; Lower than EU/EEA average for transmission, CD4 count at diagnosis, country/region of birth
Acceptability			
	Barriers to clinicians reporting HIV cases	Time constraints, inadequate reporting infrastructure, and complexity of reporting processes listed as barriers	Many EU/EEA countries also list time constraints (16/24), while some list inadequate reporting infrastructure (7/24), complexity of reporting processes (4/24), and lack of training (5/24)
	Barriers to laboratories reporting HIV cases	Time constraints and complexity of reporting processes listed as barriers	Some EU/EEA countries also list time constraints (4/24) and complexity of reporting processes (3/24)
Usefulness			
	Annual HIV continuum of care estimates	Last estimates are from 2018	All EU/EEA countries have more recent estimates
	HIV continuum of care estimates for key populations	No key population estimates for any stage of the HIV continuum of care are reported as part of Dublin declaration monitoring	One or more stages were reported by other EU/EEA countries for: MSM=17 countries; PWID=15 countries; migrants=11 countries; sex workers=3 countries; prisoners=8 countries
	Can identify and link AIDS cases occurring after HIV infection	Yes	Most EU/EEA countries can do this (20/24)
	Can identify previous positive cases	Yes	Most EU/EEA countries can do this (18/24)
	Can report on deaths among cases reported to the HIV surveillance system	Can report date of death but not cause of death	8/24 countries can report on the date and cause of death while 7/24 can report only the date of death
Simplicity			
	The ease and straightforwardness with which the HIV surveillance system can be understood, implemented, and maintained.	There is a centralised database with case notifications from clinicians and laboratory reports, though manual data. The low data linkage is due to underreporting by clinicians and/or biologists, resulting in approximately 51% to 75% of cases being linked. Once cases are reported by both biologists and clinicians, the data can be linked easily. Despite secure data transfer and management procedures, challenges include limited system interoperability, technical issues in data matching, and barriers faced by clinicians and laboratories in reporting.	France appears to face more challenges in this area than other EU/EEA countries
Representativeness			
	Geographical coverage	100%	21/24 EU/EEA countries report 100% coverage
	Under-reporting in general and by clinicians	Estimated at 43% in general, 56% among clinicians	France is among the countries with the highest overall underreporting in the EU/EEA
	Under-reporting by laboratories	52%	8% average of the 16 countries that also reported that laboratories report
	Use of any method to estimate the extent of underreporting	Yes	Only 8/24 countries have a method in place to assess the level of underreporting

*		France	EU/EEA (24 countries)
	Can identify key populations for HIV prevention	Yes (captures data on MSM, PWID, people born abroad, and transgender people)	Most EU/EEA countries' reporting systems capture data on MSM, PWID, people born abroad. 10/24 countries capture data on transgender people
Timeliness			
	Guidelines to specify the maximum timeframe to notify HIV cases	No	11/24 EU/EEA countries have standards for the maximum transmission time of results
	Current notification time from diagnosis to report to the national system	100 days	EU/EEA average=137 days (range 0-999)
Communication methods			
	Frequency of communication of surveillance results	Annually	15/24 countries communicate annually; 2/24 biannually; 1/24 quarterly; 2/24 monthly
	Methods of communication	Epi bulletins, scientific articles, website	Most countries use a variety of methods including epi bulletins, scientific articles, websites; some countries also use dashboards (7/24) and social media (8/24)
Evaluation processes			
	Internal evaluation conducted	Yes, in 2019	Seven EU/EEA countries, including France, have conducted an internal evaluation
	External evaluation conducted	Present evaluation	Five EU/EEA countries, including France, have conducted/are conducting and external evaluation

**Red=major issues noted as compared to other EU/EEA countries and European surveillance standard; Yellow=some deviations or areas where closer examination may lead to improvements; Green=areas where the system is performing well and in line with or above the EU/EEA average*
TESSy=the European Surveillance System; MSM=men who have sex with men; PWID=people who inject drugs.
The data in this table for countries other than France are provisional. Therefore, slight changes in the data displayed for those countries could occur when the full report from the Survey of EU/EEA HIV surveillance focal points is published.

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