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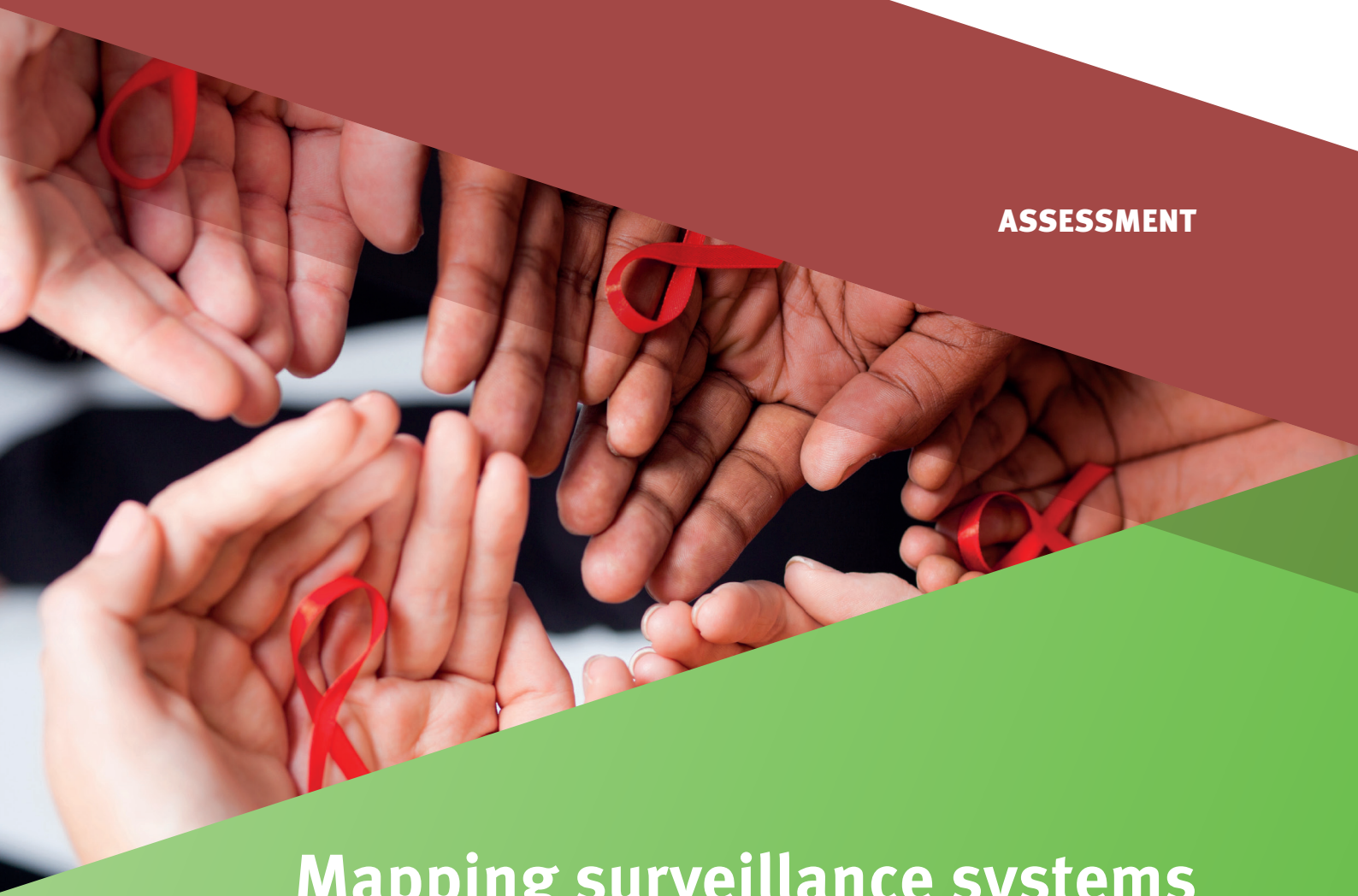

ASSESSMENT

Mapping surveillance systems for HIV/AIDS in the EU/EEA

2025

ECDC ASSESSMENT

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Erratum (5 September 2025) – Page 12: The mention of Estonia was removed in the first paragraph as this was inaccurate. In Table 9, Figures for Romania were corrected in the third and fourth columns.

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Contents

Tables

Abbreviations

AIDS	Acquired immunodeficiency syndrome
ECDC	European Centre for Disease Prevention and Control
EU	European Union
EU/EEA	European Union/European Economic Area
HIV	human immunodeficiency virus
OASIS	Outcome and Assessment of Surveillance Indicators and Systems
SDG	Sustainable Development Goals
TESSy	The European Surveillance System
WHO	World Health Organization

Executive summary

Effective surveillance is crucial for tracking HIV/AIDS trends, informing prevention efforts, and guiding healthcare planning. Routine HIV and AIDS data collection also supports risk analysis, incidence modelling, and policy development, while monitoring key sustainable development goal indicators, (such as SDG 3.3 – 'End the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases)'. Regular evaluations ensure surveillance systems remain accurate, efficient, and sustainable. This survey mapped and analysed HIV/AIDS surveillance across European Union (EU) and European Economic Area (EEA) countries and identified gaps and areas for improvement.

The survey was based on the Outcome and Assessment of Surveillance Indicators and Systems (OASIS) methodology and adapted for HIV surveillance using a semi-quantitative tool with 107 questions to evaluate organisational and functional aspects. Organisational attributes assessed the structure and management of the surveillance system, including objectives, governance, resources, stakeholder involvement, and data management. Functional attributes evaluated acceptability, usefulness, representativeness, and timeliness in system performance. A questionnaire was distributed to nominated national focal points in each EU/EEA country, with responses stored in ECDC's system.

Several areas for improvement were identified:

- **Establish, regularly review and update surveillance objectives and protocols to ensure alignment with current public health priorities:** the survey found that some EU/EEA countries have outdated HIV surveillance objectives and reporting protocols and a few other countries lack them entirely.
- **Strengthen governance frameworks and enhance stakeholder engagement:** there was an absence of a clearly defined governance structure or dedicated surveillance steering committee in some countries which limits effective coordination and decision-making. Addressing this would improve the overall impact of HIV surveillance.
- **Improve technical infrastructure and advanced digital solutions:** some countries reported gaps in secure electronic data transfer, system interoperability, and the integration of laboratory and epidemiological data, which hinders the efficiency and accuracy of HIV surveillance.
- **Streamline reporting systems, enhance training, and provide stronger support for healthcare providers and staff in laboratories:** most countries identified time constraints as the primary barrier to reporting. Some cited inadequate infrastructure, complex reporting processes, and insufficient training for clinicians and those working in laboratories as contributing factors to underreporting.
- **Implement standardised approaches to measure and address underreporting:** A high level of underreporting was noted by some countries; however, many countries reported not using any formal methodology to quantify its extent. There is a need to to ensure more accurate and representative surveillance.
- **Make surveillance systems more adaptable, streamline data integration, and leverage new health technologies:** Many countries struggle to collect key data such as death records, dates of death, AIDS diagnoses after an HIV diagnosis, and previous positive cases, revealing significant gaps in HIV surveillance.
- **Regular evaluation and continuous improvement of surveillance systems:** The lack of regular internal and external evaluations in several countries limits opportunities for performance improvement, showing the need for systematic assessment processes to ensure HIV surveillance systems remain effective, reliable, and adaptable.

Background

Surveillance is critical to understanding the epidemiology of HIV and AIDS, and collecting routine surveillance data, including HIV and AIDS case surveillance, can be used to inform and evaluate HIV prevention and response measures and to support healthcare planning. Surveillance data on HIV and AIDS diagnoses supports risk analysis, facilitates modelling for estimating HIV incidence and the undiagnosed fraction, and enables trend monitoring both overall and within specific key populations. Additionally, it informs policy recommendations based on comprehensive risk assessments and supports the monitoring of key sustainable development goals (SDG) targets such as 3.3 ('End the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases') as well as HIV targets within the WHO's Regional Action Plan [1]. EU countries submit annual HIV surveillance data to The European Surveillance System (TESSy), where they are analysed by the European Centre for Disease Prevention and Control (ECDC) and published in the annual HIV surveillance report [2], contributing to a coordinated regional understanding of the epidemic.

Surveillance systems require regular evaluation to ensure that they are operational, efficient, accurate and effectively meet surveillance objectives. Periodic assessments enable the identification of potential shortcomings, allowing for timely adjustments and enhancements to optimise system performance. By adopting a systematic approach to evaluation, stakeholders can proactively address challenges, ensure the reliability of data collection, and streamline resource allocation. Regular evaluation underscores the significance of maintaining surveillance systems that not only meet operational standards, but prove to be efficient and economically sustainable over time.

Purpose and objectives

The objective of this survey is to comprehensively characterise and map the existing surveillance systems for HIV/AIDS within the EU/EEA. This analysis aims to identify key components, methodologies, and data sources utilised in the current systems. The scope encompasses an examination of the overall structure, data collection methods and reporting mechanisms of HIV/AIDS across the EU/EEA region. This analysis takes place within the context of the new EU Regulation on Serious Cross-Border Threats to Health (2022)[i], which offers an opportunity for ECDC and national surveillance authorities to redefine the scope of infectious disease surveillance. The regulation underscores the importance of enhancing Member States' capacity for data collection and data-sharing, and calls for the development of disease-specific European surveillance standards (Chapter III, Article 13) [3].

Specific objectives

- Conduct a detailed examination of the current existing surveillance systems for HIV/AIDS, focusing on the methodologies, technologies, and data collection mechanisms in place.
- Analyse and characterise the protocols and procedures employed in data collection within surveillance systems, including data sources, frequency of reporting, and responsible entities.
- Assess the organisational and functional attributes of HIV surveillance systems.
- Benchmark existing surveillance systems to identify current practices and standards in HIV/AIDS surveillance, to highlight areas for improvement.

Methods

Framework

The framework used was based on the OASIS methodology and adapted to the specific situation of HIV [4]. We developed a semi-quantitative questionnaire to display multilevel results in a standardised way. A set of 107 questions assessed organisational and functional attributes of HIV surveillance systems. The tool was adapted in February–March 2024 with input from national focal points specialising in HIV surveillance. To ensure its relevance, clarity, and practical applicability, the tool was then pre-tested and validated in collaboration with a selected group of these focal points and experts.

i Regulation (EU) 2022/2371 of the European Parliament and of the Council of 23 November 2022 on serious cross-border threats to health and repealing Decision No 1082/2013/EU.

Organisational attributes

These attributes include an evaluation of the organisational structures and management of the surveillance system such as:

- the existence of clear, relevant objectives.
- the existence of a steering committee and clearly defined roles and responsibilities and human resources, stakeholder involvement.
- the existence of effective processes for data management and dissemination of information.

Functional attributes

Functional attributes, which in this assessment include acceptability, usefulness, representativeness and timeliness, are described below.

- **Acceptability** refers to the willingness of people and organisations to participate in the surveillance system, and the degree to which each of these users is involved in the surveillance [1]. This attribute is a critical function of a potent 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 the system.
- **Usefulness** refers to HIV surveillance system 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 value 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 populations at higher risk of acquiring HIV, monitor the impact of prevention and treatment programs, and contribute to the overall improvement of HIV-related outcomes. A highly utility-focused HIV surveillance system ensures that the data collected are not only accurate and timely but also serve the specific needs of people living with HIV, policy-makers, 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.
- **Representativeness** is the extent to which the characteristics of the population of interest are reflected by the population included in the surveillance activity and may include geographical coverage or inclusion of key populations.
- **Timeliness** is 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.

Questionnaire

The questionnaire was distributed via a link to the national surveillance focal point of each country. Information from each country was provided by a designated person responsible for collating all the required data. The information provided by countries was stored in ECDC's system.

Statistical analysis

Descriptive statistics were calculated to summarise key aspects of the HIV surveillance systems in each country. This involved calculating frequencies and percentages for surveillance attributes. Comparative analysis was performed to identify similarities and differences in HIV surveillance processes and attributes across countries.

Findings

Out of the 30 EU/EEA countries, 25 responded (Austria, Belgium, Croatia, Cyprus, Czechia, Denmark, Estonia, Finland, France, Germany, Greece, Ireland, Italy, Liechtenstein, Lithuania, Luxembourg, Malta, Netherlands, Norway, Poland, Portugal, Romania, Slovenia, Spain and Sweden) by 6 June 2024.

Organisational attributes

Structure, documentation, and composition of the HIV surveillance systems

Among the 25 countries that responded, 22 indicated the presence of a national network, where decisions regarding the surveillance system are made at the national level. Sweden reported a mixed approach, where coordination is led by regional authorities but final decisions rest nationally. In Luxembourg, coordination involves laboratories, and the specialised national infectious diseases hospital unit, and public health authorities, whereas in Spain, HIV surveillance at the national level is overseen by national authorities, while regional authorities manage implementation and data collection within their territories.

Twenty-three countries have defined objectives for their HIV surveillance systems. Austria and Lithuania did not have defined objectives. Eight countries reported that their objectives remain fully aligned with current HIV information needs. Eleven countries indicated general alignment but noted minor deficiencies. Four countries acknowledged that, while their objectives are broadly aligned with current needs, there are significant gaps or major deficiencies that require attention (Table 1). Fifteen countries responded that they are planning to update their HIV surveillance objectives, six replied that there were no plans, and the remaining countries did not respond to the question (data not shown).

Regarding the legal framework and the document defining the roles of the actors involved in the surveillance system, all 25 countries indicated that their HIV surveillance system is formalised within national legislation. Nineteen countries reported having a document that comprehensively defines the roles of different partners within the surveillance network and six do not have any such document (data not shown).

Table 1. EU/EEA country assessment of surveillance system objectives in relation to current HIV context and information needs

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

Austria and Lithuania did not respond to this question.

Eleven countries reported having a steering committee in place, defined as the entity playing a pivotal role in setting the orientation and objectives of the network, as well as making strategic decisions. It comprises the main decision-making bodies involved in surveillance. Conversely, 14 countries do not have this group established.

Eighteen countries reported having a documented surveillance protocol for reporting cases within their respective countries. Conversely, three countries (Austria, Cyprus and Greece) lack such a protocol. Additionally, the person reporting for Malta, the Netherlands, and Norway was uncertain about the existence of such a document. Furthermore, one county did not respond to this question. Among those countries with a reporting protocol in place, 13 stated that their protocols are up to date and aligned with the current HIV context, whereas Estonia, France, Italy and Luxembourg stated that their protocols were not up to date. Twenty-three countries reported using the ECDC definition for HIV, while France and Sweden employ a distinct definition.

All countries responded that they have a centralised team or organisation responsible for overseeing the entire HIV surveillance system. The activities carried out by the centralised team or organisation overseeing the entire HIV surveillance system include data analysis (25 countries), communication of results (25 countries), data management (24 countries), data validation (22 countries), and, to a lesser extent, modelling (i.e. generating incidence estimates, or people living with HIV estimates) (17 countries) and other activities that included following up on observational cohort studies, responding to media inquiries in coordination with the Ministry of Health, and actively engaging in service provision for policy-makers and other relevant stakeholders (four countries) (Table 2).

Table 2. EU/EEA country assessment of HIV surveillance systems: activities of the central team or organisation overseeing national HIV surveillance by country, 2024

Country	Data management	Data validation	Data analysis	Modelling (i.e. generating incidence estimates, or people living with HIV estimates)	Communication of results	Other
Austria						
Belgium						
Croatia						
Cyprus						
Czechia						
Denmark						
Estonia						
Finland						
France						
Germany						
Greece						
Ireland						
Italy						
Liechtenstein						
Lithuania						
Luxembourg						
Malta						
Netherlands						
Norway						
Portugal						
Romania						
Slovenia						
Spain						
Sweden						

Green indicates that the activity was reported by the country
White indicates that the activity was not reported by the country

Tools and technical resources

Twenty-one countries have a case notification form in place for reporting, 14 countries offer direct database access for reporting, and six countries have dashboards to display data to clinicians and laboratories (Table 3). It is important to note that no country provides a fee or incentive to clinicians and/or laboratories for reporting a new case.

Table 3. EU/EEA country assessment of HIV surveillance systems: available resources to support clinicians and laboratories in effective data management by country, 2024

Country	Case notification form	Direct access point for clinics and/or laboratories to the database	Dashboards	Other
Austria				
Belgium				
Croatia				
Cyprus				
Czechia				
Denmark				
Estonia				
Finland				
France				
Germany				
Greece				
Ireland				
Italy				
Liechtenstein				
Lithuania				
Luxembourg*				
Malta				
Netherlands				
Norway				
Poland				

Country	Case notification form	Direct access point for clinics and/or laboratories to the database	Dashboards	Other
Portugal				
Romania				
Slovenia				
Spain				
Sweden				

Green indicates that the activity was reported by the country.
White indicates that the activity was not reported by the country.
** In Luxembourg, laboratories submit electronic notifications. However, there is currently no medical case notification system in place.*

Countries highlighted limitations in their databases, including the challenges of managing clinic network study cohorts originally established for research purposes and overseen by clinicians. In such cases, as seen in Austria, clinicians lack a legal mandate to report new HIV diagnoses. As a result, data-sharing with national surveillance systems relies on mutual understanding rather than a formal legal framework, limiting the consistency and completeness of data collection. There is agreement among some countries on the need for an automated data visualisation platform. Concerns include the absence of automatic statistical analysis and limited communication with stakeholders. Incomplete submissions by clinicians result in missing data, and data protection frameworks restrict export of data. Disparities in reporting infrastructure and separate databases for HIV and AIDS cases are noted, alongside slow system upgrades.

Twenty-four countries reported having a centralised database within their national surveillance system. In addition, 13 countries have implemented an electronic reporting system that automatically gathers and sends data to the centralized database. However, Cyprus, Czechia, Germany, Lithuania, Malta and Slovenia rely on traditional paper-based reporting forms, which healthcare facilities submit to regional and national health departments. Austria, Luxembourg, Ireland, the Netherlands, Portugal, and Spain have alternative systems in place to collect and aggregate data at the national level, each employing a distinct approach to implementation. These six countries use diverse methods for transferring data to their national surveillance systems.

In Austria, an electronic reporting system is employed, transmitting data directly to the cohort centralised database. Laboratories in Austria submit the number of HIV tests and positives results through paper-based reporting forms, which are then forwarded to the Ministry of Health. In Ireland, laboratories electronically notify HIV cases to the Computerised Infectious Disease Reporting system, with enhanced data manually inputted into the system. Luxembourg relies on its national infectious diseases unit's hospital database for data management. In the Netherlands, people diagnosed with HIV are notified by the country's HIV treatment centres, with data sourced from electronic patient files, using both manual entry and automated import methods. Portugal uses an electronic data collection system, with data aggregation performed through registration in a separate manual database. Lastly, Spain gathers data through databases submitted by public health regional autonomous communities.

Countries with laboratories reporting to their HIV surveillance systems

From the 19 countries where laboratories were reporting at the time of the questionnaire, Finland, Luxembourg, Malta, Norway, and Romania have automated reporting systems. Conversely, in Czechia, France, Germany, Greece, Lithuania, Poland and Slovenia, reporting from laboratories require manual entry by laboratory staff, however in Poland reporting methods vary by laboratory, notifications are mostly sent in paper form, either generated from local systems or manually completed, but transition to electronic reporting is planned for 2025, with options for automatic, semi-automatic, or manual data entry into the central database. In Belgium, Denmark, Estonia, Ireland, and Liechtenstein, reporting is semi-automated with some manual input required. Additionally, in Portugal and Sweden, the reporting methods vary depending on the laboratory. In Portugal, although laboratory reporting is always electronic it can be done automatically (webservice/interface) or by manual entry at a specific webpage.

The proportion of laboratory data that can be linked with epidemiological data is approximately 51-75% in France, Estonia and Poland and over 75% in the 13 remaining countries, except for Malta and Portugal where the proportion is unknown.

The primary barriers to linking laboratory data, as reported by countries, vary significantly. In Czechia, the main obstacles include a lack of interoperability between systems and limited resources for data integration. In France, the primary barrier is underreporting by clinicians, which results in the absence of epidemiological data to link with some laboratory data. Additionally, both Czechia and France reported technical challenges in data matching as a significant barrier. Germany identifies legal or regulatory restrictions as its main issue, while Luxembourg and Romania report that they struggle primarily with the absence of standardised protocols.

Eight countries (Belgium, Estonia, Finland, France, Ireland, Liechtenstein, Norway, and Sweden) report that they have established secure electronic data systems dedicated to transferring laboratory data to the national surveillance system. Conversely, Czechia, Denmark and Lithuania rely on manual data entry into surveillance databases for data transmission. In Greece, Luxembourg, Portugal, and Romania, data transfer occurs through automated interfaces between laboratories and the surveillance system. In Germany and Malta, laboratories submit paper forms of reports for data transmission and in Poland, the transition to electronic reporting is planned for 2025, offering options for automatic, semi-automatic, or manual data entry into the central database, enhancing data linkage between laboratory and epidemiological records.

Data management

Twenty-three countries reported having structured data management procedures in place, which include data validation and secure storage within databases. Cyprus and Malta indicated they do not have such procedures established. In Annex 3 Table 1 there is a concise overview of the data management procedures implemented by countries to handle HIV surveillance data.

Countries face numerous challenges in data analysis, including limited number of variables, time constraints, and understaffing. In some countries fragmented healthcare systems and data protection regulations further complicate analysis. Shortfalls in resources and personnel exacerbate these challenges, particularly in accessing complete clinical datasets (Table 4).

Table 4. EU/EEA country assessment of HIV surveillance systems: available resources to support clinicians and laboratories in effective data management by country, 2024

Country	**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
Austria						
Belgium						
Croatia						
Cyprus						
Czechia						
Denmark						
Estonia						
Finland						
France						
Germany						
Greece						
Ireland						
Italy						
Liechtenstein						
Lithuania						
Luxembourg						
Malta						
Netherlands						
Norway						
Poland						
Portugal						
Romania						
Slovenia						
Spain						
Sweden						

Green indicates that the activity was reported by the country.
White indicates that the activity was not reported by the country.

Various unique identifiers, including social health insurance numbers, pseudonymised national register numbers, personal identification numbers, names, and social security numbers, are used in HIV surveillance systems. Patient-specific data such as names, dates of birth, and specimen identification numbers (IDs) are also employed. In Germany, alphanumeric HIV codes are being transitioned to electronic systems. For instance, in one country, identification methods may vary regionally, including ID numbers, dates of diagnosis, and could be also free text (Annex 1 Table 2). In 12 countries, the identifier utilised in surveillance systems can be employed to trace back to personal information from other sources. Conversely, in 10 countries, linking back with other sources of information using the identifier is not possible. In Spain, identifiers such as social security numbers or clinical record numbers are used at regional level for data management, while in Poland linkage is impossible due to legal and technical constraints, as cases are often reported without a national ID, the primary identifier in the healthcare system.

Out of the 25 countries surveyed, 22, have the capability to identify and eliminate duplicates within their surveillance systems. Sweden faces challenges in this regard, as it is unable to identify duplicates. Poland uses a manual process to eliminate duplicates, relying on date of birth, Universal Electronic System for Registration of the Population (PESEL) number, HIV test number and/ or case codes. Greece did not respond to this question.

The types of unique identifiers used by laboratories to identify samples vary significantly across countries, as illustrated in Annex 1 Table 3. All countries with laboratories reporting can successfully identify two positive tests belonging to the same person.

Functional attributes

Acceptability

Acceptability was not directly assessed in this survey, as this mapping is based on a qualitative assessment provided by the national focal point of each country. Hence, evaluating the willingness of people (clinicians and/or laboratories) and organisations who use or provide data to accept the system and participate in it was not performed. Nevertheless, indirect questions were included to evaluate the primary barriers to high acceptability among clinicians and laboratories. The primary barriers to clinicians and laboratories reporting newly diagnosed HIV cases to the surveillance system include time constraints (19 countries), inadequate reporting infrastructure (seven countries), followed by the complexity of the reporting process (five countries), lack of training (six countries). For countries where laboratories report newly diagnosed HIV cases to the surveillance system, the reported barriers were time constraints (five countries) and the complexity of the reporting process (three countries) (Tables 5 and 6).

Specific barriers were reported by other countries. For example, Austria reported that clinicians lack a legal mandate to report new HIV diagnoses. However, such cases can still be identified through cohort studies, as the national surveillance system relies on a clinical cohort. Additionally, clinicians may face time constraints and insufficient reporting infrastructure, which can hinder effective data collection. While in Ireland it was reported that data management resources are limited, with reliance on paper-based records and the absence of electronic health records.

Table 5. EU/EEA country assessment of HIV surveillance systems: reported barriers to clinicians in reporting newly diagnosed HIV cases, 2024

	Clinicians							
Country	Time constraints	Privacy concerns	Complexity of reporting process	Lack of training	Inadequate reporting infrastructure	Fear of stigma	Other	Not Applicable
Austria								
Belgium								
Croatia								
Cyprus								
Czechia								
Denmark								
Estonia								
Finland								
France								
Germany								
Greece								
Ireland								
Italy								
Liechtenstein								
Lithuania								
Luxembourg								
Malta								
Netherlands								

	Clinicians							
Country	Time constraints	Privacy concerns	Complexity of reporting process	Lack of training	Inadequate reporting infrastructure	Fear of stigma	Other	Not Applicable
Norway								
Poland								
Portugal								
Romania								
Slovenia								
Spain								
Sweden								

Green indicates that the activity was reported by the country
White indicates that the activity was not reported by the country
Grey indicates that clinicians do not report to the HIV surveillance system.

Table 6. EU/EEA country assessment of HIV surveillance systems: reported barriers to laboratories in reporting newly diagnosed HIV cases, 2024

	Laboratories						
Country	Time constraints	Privacy concerns	Complexity of reporting process	Lack of training	Inadequate reporting infrastructure	Fear of stigma	Other
Austria							
Belgium							
Croatia							
Cyprus							
Czechia							
Denmark							
Estonia							
Finland							
France							
Germany							
Greece							
Ireland							
Italy							
Liechtenstein							
Lithuania							
Luxembourg							
Malta							
Netherlands							
Norway							
Poland							
Portugal							
Romania							
Slovenia							
Spain							
Sweden							

Green indicates that the activity was reported by the country
White indicates that the activity was not reported by the country
Grey indicates that laboratories do not report to the HIV surveillance system.
Note: In Spain, laboratories report to the HIV surveillance system at the regional level, but not at the national level. In Belgium: clinicians report care data and therefore contribute to the surveillance system. However, they do not report newly diagnosed HIV cases.

Usefulness

Usefulness refers to the capacity of a surveillance system to provide valuable, relevant, and actionable information supporting public health efforts in understanding, preventing, and managing HIV infections, as described in the methods section. In this context, we explore the system's capacity to identify key populations at higher risk of acquiring HIV (detailed under the representativeness attribute) and its efficacy in identifying previous positive diagnoses[ii] for individual analysis. Furthermore, usefulness extends to 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.

ii Previous positive diagnoses are defined as an HIV diagnosis made either abroad or in another setting within the reporting country on any occasion before the current year of reporting. Some countries report previous positive HIV cases as they enter, re-enter or re-engage with the care system in the reporting country

All countries have the capacity to identify men who have sex with men, people who have injected drugs and migrants, whereas 14 countries can provide information on transgender people, 18 countries can provide information for sex workers, and nine can monitor people who have been in prison (Table 7).

Table 7. EU/EEA country assessment of HIV surveillance systems: key populations identified by surveillance systems by country, 2024

Country	Men who have sex with men	People who have injected drugs	Sex workers	Transpeople	People who have been in prison	Migrants	Other
Austria							
Belgium							
Croatia							
Cyprus							
Czechia							
Denmark							
Estonia							
Finland							
France							
Germany							
Greece							
Ireland							
Italy							
Liechtenstein							
Lithuania							
Luxembourg							
Malta							
Netherlands							
Norway							
Poland							
Portugal							
Romania							
Slovenia							
Spain							
Sweden							

Grey indicates countries that did not provide information
Green indicates the key populations identified by surveillance systems by country
White indicates those key populations which are not identified by surveillance systems by country

In terms of previous positive HIV diagnoses, 19 countries have the capability to identify them. Luxembourg, Poland, Spain and Sweden face challenges in this regard, as they are unable to identify previous positive diagnoses. Two countries did not respond to this question.

Twenty-two countries can collect AIDS data occurring downstream after HIV notification. In Denmark for instance, AIDS is no longer a notifiable condition. However, historical AIDS notifications are being linked to current HIV notifications, and new AIDS-defining diagnoses continue to be monitored annually, despite the removal of mandatory reporting. Two countries face challenges in this regard. In Portugal, the system requires a new notification for AIDS, separate from HIV, in the electronic reporting system, that is then matched with the original HIV notification, allowing the AIDS-stage related data to be added. Conversely, in Ireland, the system is designed to collect AIDS-defining illnesses at the time of HIV diagnosis, as HIV is notifiable, not AIDS. One country did not respond to this question.

Thirteen countries can retrieve both the date and cause of death whereas eight countries only retrieve the date of death. Italy stands out as the only country able to retrieve the cause of death without the date of death (Table 8). Sources of information used to retrieve mortality data include manual notification systems, involving individual searches across various data sources to determine vital status, as well as national death registries, entailing linkage with national death registries or vital statistics systems, other sources were reported by three countries but were not specified. Nine countries updated death data annually, while 13 countries did not specify the periodicity for the updates.

Table 8. EU/EEA country assessment of HIV surveillance systems: countries' capacity for collecting mortality data, data sources, and update frequencies, 2024

Country	Date of death	Cause of death	Source of information used to retrieve mortality data	Updating frequency
Austria			National Death Registries: linkage with national death registries or vital statistics systems	Annual
Belgium			Other	Annual
Croatia			Other	No periodicity specified
Cyprus			Not provided	Annual
Czechia			Manual notification systems: searching various data sources to determine vital status	No periodicity specified
Denmark			National Death Registries: linkage with national death registries or vital statistics systems	Annual
Estonia			N/A	No periodicity specified
Finland			Not provided	Annual
France			Date of death is collected via mandatory manual notification	No periodicity specified
Germany			N/A	N/A
Greece			National Death Registries: linkage with national death registries or vital statistics systems	Weekly
Ireland			The date and cause of death are included in the enhanced surveillance forms and are reported only if the death occurred at the time of HIV diagnosis.	No periodicity specified
Italy			National Death Registries: linkage with national death registries or vital statistics systems	Annual
Liechtenstein			Not provided	No periodicity specified
Lithuania			National Death Registries: linkage with national death registries or vital statistics systems	Annual
Luxembourg			N/A	No periodicity specified
Malta			Date and cause of death is extracted from national mortality registry	N/A
Netherlands			Health Records and Medical Facilities: linkage with health records from hospitals, clinics, and other medical facilities	No periodicity specified
Norway			Not provided	No periodicity specified
Poland			N/A	N/A
Portugal			Notification of HIV, AIDS, and death among people living with HIV is mandatory. The system requires a new notification for death, that is then matched with the original HIV notification and date of death registered in the database	No periodicity specified
Romania			Other	Annual
Slovenia			HIV Surveillance system and the National Death Registries	No periodicity specified
Spain			Mortality data come from regional HIV surveillance systems. It is not possible to link the national database with the vital statistics system	No periodicity specified
Sweden			Not provided	No periodicity specified

Green indicates countries' capacity for collecting mortality data
White indicates countries lack mortality data
Grey indicates countries that did not provide information
N/A: Not applicable

Countries have reported various barriers to updating the vital status of people living with HIV in the surveillance system. Germany highlights delays in receiving official death certificates or mortality reports from relevant authorities. Ireland and Luxembourg cite insufficient human, financial, or technological resources as challenges. Additionally, there is a lack of interoperability among systems, hindering the seamless flow of vital status updates. Luxembourg also points out legal and regulatory constraints.

Representativeness

Regarding the coverage of the HIV surveillance system, 23 out of 25 countries reported 100% geographical coverage. Austria stated that its surveillance system covers only 75% of the territory. France, Germany and Austria were among the countries with the highest overall underreporting in 2024 (Table 9). Despite most countries in the survey acknowledging the existence of underreporting, 14 countries indicated that they do not conduct any assessment or estimation of underreporting. 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. Belgium does not make such estimations because its surveillance system is designed to be comprehensive and exhaustive.

Table 9. EU/EEA country assessment of HIV surveillance systems: estimated proportion of underreporting of HIV new diagnosis by clinicians, regional authorities, and laboratories by country, 2024

Country	Underreporting in general (%)	Underreporting by clinicians (%)	Underreporting by regional authorities (%)	Underreporting by laboratories (%)
Austria	36	-	-	-
Belgium	0			0
Croatia	1	-		
Cyprus	0	0		
Czechia	2	-	-	1
Denmark	15	15		10
Estonia	-	50		-
Finland	4	20		0
France	43	56		52
Germany	30	40		20
Greece	0	-		0
Ireland	5	0	0	5
Italy	10	10	5	
Liechtenstein	0	2		0
Lithuania	5	-	5	5
Luxembourg	0	0		0
Malta	5	-		5
Netherlands	3	3	-	
Norway	0	-		0
Poland	-	-	-	-
Portugal	-	-	-	-
Romania	10	10	10	0
Slovenia	0	0		0
Spain	-	-	-	
Sweden	1	1	1	2

Gray indicates that countries lack intermediary regional authorities responsible for reporting or collecting data, and/or laboratories contributing data to the surveillance system.
- Data not provided
Note: Countries use varying methods to assess or estimate underreporting, with many having no formal methodology. Therefore, comparisons between countries should be interpreted with caution.

Timeliness

In terms of timeliness, we only asked for the time it takes for clinicians to report cases to the national surveillance system. In Belgium, however, timeliness refers to the duration laboratories take to report, as they do not submit data per diagnosis, instead, they report all diagnoses from the previous year in a single annual batch. In this regard, 14 countries reported having existing guidelines specifying a standard time frame for the maximum transmission time of case reporting. Conversely, 10 countries do not have this standardised time frame defined in any document. Austria and Luxembourg, where the surveillance system is based on cohort data, find this type of standardised time not applicable (Table 10).

The mean time stipulated in guidelines for the transmission of reports from clinicians to the national surveillance systems among the nine countries that provided this information was 62 days (range: 1-365). However, the actual mean notification time was 137 days (range: 0-180). Notably, among the countries that reported a time frame for notification, there were no delays observed in reporting from clinicians.

Table 10. EU/EEA country assessment of HIV surveillance systems: comparison of guideline-defined transmission time and actual notification time for clinicians/laboratories reporting cases to the national surveillance system by country, 2024

Country	Guideline-defined transmission time in days	Current notification time (in mean 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	7	30
Luxembourg	-	-
Malta	-	30
Netherlands	-	-
Norway	-	-
Poland	1	40
Portugal	1	122
Romania	10	30
Slovenia	3	90
Spain	-	-
Sweden	1.5	2

Data not provided
** In Belgium, a predefined data collection period is established during which laboratories upload data from the previous year. As a result, these timeliness metrics do not apply to their reporting system.*

Communication methods

Twenty-two countries regularly publish reports and/or scientific articles on surveillance results obtained from their respective surveillance systems. Luxembourg does not publish reports, and two countries did not respond to this inquiry. Among the respondents, 17 countries report their results annually. The Netherlands and Romania release reports every six months, and Malta issues them quarterly. Czechia and Ireland provide monthly updates on surveillance findings.

The dissemination of surveillance results and data typically target various audiences, including the general public, clinicians, civil society, researchers, politicians, and key populations. Neighbouring countries are among the least targeted population for communication purposes (Table 11).

Table 11. EU/EEA country assessment of HIV surveillance systems: target audiences defined in national communication strategies by country, 2024

Country	General public	Neighbouring countries	Network members	Clinicians	International organisations	Private and public national partners	Civil society	Politicians	Laboratories	Researchers	Key populations	other
Austria												
Belgium												
Croatia												
Cyprus												
Czechia												
Denmark												
Estonia												
Finland												
France												
Germany												
Greece												
Ireland												

Country	General public	Neighbouring countries	Network members	Clinicians	International organisations	Private and public national partners	Civil society	Politicians	Laboratories	Researchers	Key populations	other
Italy												
Liechtenstein												
Lithuania												
Luxembourg												
Malta												
Netherlands												
Norway												
Poland												
Portugal												
Romania												
Slovenia												
Spain												
Sweden												

Green indicates targeted audiences defined in national communication strategies by country
White indicates non-targeted audiences defined in national communication strategies by country

To communicate surveillance results, countries use websites (24 countries) and epidemiological bulletins or reports (22 countries), followed by scientific articles (15 countries), social media (nine countries), and dashboards (seven countries) (Table 12).

Table 12. EU/EEA country assessment of HIV surveillance systems: methods used to communicate surveillance results by country, 2024

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						
Lithuania						
Luxembourg						
Malta						
Netherlands						
Norway						
Poland						
Portugal						
Romania						
Slovenia						
Spain						
Sweden						

Green indicates methods used to communicate surveillance results by country
White indicates methods not used to communicate surveillance results by country

Evaluation processes

Internal evaluation

Seven countries reported having conducted an internal evaluation, while 13 countries have never done so. Additionally, for two countries, the person responding was uncertain whether such evaluations had been conducted, and one country did not respond to this question. The methods employed vary, but they are primarily based on ECDC guidelines. These evaluations have been carried out between 2015 and 2024, encompassing various surveillance attributes (Table 13).

Table 13. EU/EEA country assessment of HIV surveillance systems: internal evaluation of HIV surveillance systems by country, 2024

Country	Internal evaluation	Method used	Date	Attributes
Austria	Not provided			
Belgium	Yes	Internal audit		Data collection, internal management and procedures
Croatia	Yes	The evaluation was carried out as part of fellowship programme of the European Centre for Disease Prevention and Control (ECDC) in field epidemiology (EPIET), according to ECDC guidelines and standards, in cooperation with an ECDC mentor from EPIET programme.	01/06/2018	Timeliness, usefulness, representativeness, completeness, simplicity
Cyprus	Don't know			
Czechia	No			
Denmark	Don't know			
Estonia	No			
Finland	No			
France	Yes	Based on CDC and ECDC methods	01/07/2019	Usefulness, simplicity, acceptability, timeliness, stability, flexibility, data quality, representativeness, sensitivity, positive predictive value
Germany	No			
Greece	No			
Ireland	Yes	EPIET Evaluation	15/01/2015	Description, sensitivity, timeliness
Italy	No			
Liechtenstein	No			
Lithuania	No			
Luxembourg	No			
Malta	No			
Netherlands	Yes	Document study, interviews, adding/adapting data collection protocols		All aspects of the surveillance system, including data collection and internal management, are evaluated in a 3-year cycle
Norway	Yes	In accordance with ECDC guidelines for surveillance system evaluation	27/01/2016	Completeness, timeliness, sustainability, cost and resources, usefulness, flexibility, feasibility, acceptability
Portugal	No			
Romania	Yes	Regular assessment of the HIV data (quarterly) and collaboration with the National Public Health Institute	31/03/2024	The data registration system through the reporting charts; evaluation of the epidemiological, clinical, laboratory data, staging, treatment data
Slovenia	No			
Spain	No			
Sweden	No			

External evaluation

External evaluations have been conducted by Belgium (in 2024), France (in 2024), Germany (in 2024), the Netherlands (in 2015), and Portugal (in 2009). These evaluations covered various attributes, including usefulness, acceptability, representativeness, flexibility, sensitivity, timeliness, data collection, use of data, internal management, data completeness, simplicity, acceptability, and stability. It is noteworthy that Germany based its evaluation on the SDG core indicators, meaning the assessment had a broader scope, covering all relevant systems—including the HIV surveillance system—to inform the development of SDG indicators.

Discussion

This survey highlights that HIV surveillance systems in EU/EEA countries collect data using diverse methods and methodologies. Although the systems differ across EU/EEA countries, they have both similar and unique challenges based on their specific attributes. This survey characterised the operational and functional attributes of the HIV surveillance systems in EU/EEA countries and described the current challenges of these systems which are critical for disease prevention, programme planning and management, health promotion, quality improvement and resource allocation. Ultimately, these systems play a crucial role in monitoring key SDG 3.3 HIV targets [5] and targets within the WHO's Regional Action Plan [6].

Shifting migration patterns and new paradigms, such as pre-exposure prophylaxis for HIV (PrEP) and HIV treatment as prevention and test-and-treat, have transformed the dynamics of HIV surveillance, highlighting the need to incorporate new data elements that were previously not considered. This context may help explain why, despite progress, many HIV surveillance systems in the EU/EEA report limitations in their current objectives. While eight countries indicated that their objectives remain fully aligned with present HIV information needs, 11 reported general alignment but noted minor deficiencies. Four countries acknowledged that although their objectives are broadly aligned, they face significant gaps or major shortcomings that require targeted improvement.

Eighteen countries have surveillance protocols available, but only 13 are up to date. This highlights the need for EU/EEA countries to align their efforts in evaluating and updating the objectives and reporting protocols of their HIV surveillance systems —or to develop them where they do not yet exist. Objectives of a surveillance system should be precisely defined, tailored to the surveillance outcomes, intended information uses, and the system's levels (local, regional, national). Processes and components must align with these objectives to ensure valid information, operational efficiency, and adherence to legal mandates [7].

In terms of governance, only 11 out of 25 EU/EEA countries currently have a surveillance steering committee in place—a figure that is suboptimal given the importance of cross-sectoral coordination in responding effectively to the HIV epidemic. A well-functioning steering committee, with active participation from key stakeholders across public health, clinical, academic, and community sectors, is essential to ensure the system remains relevant and responsive to epidemiological trends. For surveillance systems to have maximum impact, it is crucial that the data collected are meaningfully used, and that the steering committee perceives the system as valuable [8]. Engaging both the committee and broader stakeholders throughout the surveillance cycle enhances the system's utility. Their involvement supports data interpretation and facilitates timely responses to emerging information.

The assessment of tools and technical resources for HIV surveillance among EU/EEA countries reveals several key findings. Case notification forms are in place in 21 out of 25 countries and direct database access for reporting is available in 14 countries. A centralised database is used by most of the 25 countries. However, when it comes to linking laboratory data with epidemiological data, the situation varies between countries. Secure electronic data transfer systems for transferring laboratory data to the national surveillance system are in place in eight out of 18 countries with laboratory data. Structured data management processes, including data validation and secure storage within databases are established in 23 out of 25 countries. Only 12 out of 25 countries can link to other sources of information based on personal identifiers used to report HIV cases. These findings highlight the varying levels of tools and technical resources across the region, with notable strengths in the use of centralised databases and structured data management processes. However, there are areas for improvement, particularly in secure electronic data transfer systems, and interoperability to retrieve data from other information sources. Additionally, enhancing the simplicity of the systems and incorporating more advanced and future-proof technological solutions could significantly increase the acceptability, timeliness and completeness of surveillance data [9].

The acceptability of HIV case reporting among EU/EEA countries faces several barriers for both clinicians and laboratories. Out of 25 countries, time constraints are reported as a significant barrier in 19 countries for clinicians and five countries for laboratory staff. Additionally, some countries cite inadequate reporting infrastructure, complexity of reporting processes, lack of training, and fear and stigma as obstacles. These barriers highlight the challenges faced in effectively reporting HIV cases, indicating a need for improved infrastructure, simplified processes, and enhanced training.

Although it was not possible to measure the usefulness of the HIV surveillance system directly due to the survey not being distributed to information users, we included proxy measures by asking about the collection of key information relevant to the current HIV context. Most countries (22 out of 25) can identify and link AIDS cases occurring after HIV infection. Additionally, 18 out of 25 countries can identify previous positive cases. In terms of mortality reporting, 21 out of 25 countries can report the date of death among cases, while 14 out of 25 can report the cause of death. AIDS cases, AIDS defining illnesses, previous positive diagnoses, and deaths are crucial for understanding the current epidemiological profile of HIV in the EU/EEA countries. Therefore, HIV surveillance systems should be adaptable to current challenges by making it easy to include or exclude information and adaptable to new health technologies. This flexibility will help maintain the relevance and effectiveness of the surveillance systems in addressing the evolving HIV landscape.

On a positive note, most EU/EEA HIV surveillance systems can identify key populations relevant for HIV prevention. They capture data on men who have sex with men, people who inject drugs in all 25 countries, migrants in 24 out of 25 countries, transgender people in 14 out of 25 countries, sex workers in 18 out of 25 countries, and people who have been in prison in nine out of 25 countries. This capability ensures that the surveillance systems can effectively inform interventions for these key populations.

The geographical coverage of HIV surveillance systems in EU/EEA countries is high, with 24 out of 25 countries reporting 100% geographical coverage. However, there are concerns about underreporting, with a median rate of 26.5% for clinicians and 13.3% in general. Only seven out of 25 countries have implemented methods to estimate the extent of underreporting, indicating a gap in accurately assessing the full scope of HIV cases. This underscores a critical priority for current HIV surveillance systems: addressing the representativity of collected data.

The timeliness of HIV case reporting in EU/EEA countries shows some areas for improvement. Out of 25 countries, 13 have guidelines specifying the maximum timeframe to notify HIV cases. Among those with guidelines, only 10 have standards for the maximum transmission time of results. The average notification time from diagnosis to reporting to the national system across the EU/EEA was 137 days at the time of the questionnaire, with a wide range from 0 to 180 days. This variability indicates significant differences in reporting times from clinicians to national services. These differences are linked to the characteristics of the data collection systems (electronic vs. paper-based) and the methods of data retrieval from laboratory databases or clinical records. Despite these disparities, timeliness was not judged by most countries to be a significant issue for their HIV surveillance systems. However, addressing these discrepancies and establishing agreed-upon timelines could further enhance the efficiency of the surveillance systems.

The communication methods for HIV surveillance results among EU/EEA countries demonstrate a robust system of regular reporting. A total of 22 countries consistently publish surveillance reports. Most countries employ a variety of channels for communication, including epidemiological bulletins, scientific articles, and websites. Additionally, some countries utilise dashboards and social media to disseminate surveillance information. These diverse methods show that surveillance results are effectively communicated to various stakeholders, enhancing the overall transparency and responsiveness of the HIV surveillance systems.

The assessment of the evaluation processes for HIV surveillance systems in the EU/EEA revealed that seven countries have conducted internal evaluations to assess their systems. Additionally, five countries have either conducted or are in the process of conducting external evaluations. These evaluations are crucial for ensuring the effectiveness and efficiency of surveillance systems, identifying areas for improvement, and maintaining high standards in monitoring and managing HIV cases. However, evaluations have only been performed in a few countries, and some were conducted several years ago. Therefore, both internal and external evaluations should be systematically included as part of the HIV surveillance process to guarantee that the systems are well-maintained and address performance issues. This represents an important area for improvement, and countries should assess how to effectively incorporate and execute these evaluation processes to ensure the continuous enhancement of their HIV surveillance systems.

Limitations

There are several limitations to the approach taken in this survey, which should be considered when interpreting its results and recommendations. HIV surveillance systems are complex, and this questionnaire may lead to the simplification of the issues or recommendations in some areas. The survey relied on the self-assessment of a single person or the working group responsible for the HIV system in each country, without broader engagement with national or regional stakeholders from EU/EEA countries. This may have introduced bias in some responses. Additionally, questions could have been interpreted or understood differently, potentially leading to errors in the comparisons presented in this analysis. The systems and the epidemiology of HIV differ substantially across the EU/EEA, making direct benchmarking challenging in some areas.

Conclusion

This survey highlights the heterogeneity of HIV surveillance systems across EU/EEA countries and underscores some of the challenges they face in collecting HIV data. While the structure and capacity of these systems vary, countries share common obstacles as well as opportunities for improvement. A number of priority areas for improvement have been identified. Some national surveillance systems operate with outdated objectives and protocols, limiting their relevance to the current epidemiological situation. This misalignment hampers the ability of public health authorities to respond effectively to evolving HIV trends. Furthermore, the absence of a clearly defined governance structure or dedicated surveillance steering committee in some countries limits effective coordination and decision-making. Technical and data management challenges also were found. These include challenges like lack of system interoperability, weak integration between laboratory and epidemiological data, and a lack of secure, standardised mechanisms for electronic data transfer. In addition, reporting barriers — such as time constraints, inadequate infrastructure, insufficient training for clinicians and laboratories, stigma, and complex procedures — may contribute to widespread underreporting. Few countries have adopted standardised methodologies to measure or address underreporting, further affecting the accuracy and completeness of surveillance data.

Other commonly reported challenges faced by surveillance systems include the inability to capture important information such as death records, dates of AIDS diagnosis following HIV diagnosis, and previously known HIV-positive cases. Additionally, the absence of regular internal and external evaluations in several countries limits opportunities for quality assurance, learning, and system improvement. To address these issues, it is essential to update surveillance objectives, enhance governance frameworks, secure adequate human and financial resources, and invest in modern digital infrastructure. Strengthening data integration, simplifying reporting processes, and improving communication with healthcare providers and other stakeholders will help improve both the efficiency and representativeness of surveillance.

In recognition of these needs, ECDC, under the framework of the Serious Cross-Border Threats to Health legislation, will initiate a review of current HIV surveillance objectives. In collaboration with the HIV Surveillance Network, ECDC will work to define updated surveillance standards in the coming years. This coordinated effort aims to ensure that HIV surveillance systems across the EU/EEA are better aligned with public health priorities, responsive to emerging trends, and equipped to support effective monitoring, prevention, and control measures. By adopting a more coordinated, adaptive, and forward-looking approach, EU/EEA countries can significantly enhance the capacity and resilience of their HIV surveillance systems—supporting progress toward national and global HIV response targets.

References

1. WHO Regional Office for Europe (WHO EURO). Regional action plans for ending AIDS and the epidemics of viral hepatitis and sexually transmitted infections 2022–2030. Copenhagen: World Health Organization; 2023
2. WHO Regional Office for Europe (WHO-EURO), European Centre for Disease Prevention and Control (ECDC). HIV/AIDS surveillance in Europe 2024 – 2023 data. Copenhagen: WHO Regional Office for Europe; 2024. https://www.ecdc.europa.eu/sites/default/files/documents/HIV_Surveillance_Report_2024.pdf
3. European Union. Regulation (EU) 2022/2371 of the European Parliament and of the Council of 23 November 2022 on serious cross-border threats to health and repealing Decision No 1082/2013/EU. Official Journal of the European Union. 2022 Dec 6;L314:26–61.
4. Hendrikx P GE, Chazel M, Moutou F, Danan C, Richomme C, Boue F, Souillard R, Gauchard F, Dufour B. OASIS: an assessment tool of epidemiological surveillance systems in animal health and food safety. Epidemiology & Infection. 2011;139(10):1486-96.
5. United Nations. Sustainable Development Goal 3: Ensure healthy lives and promote well-being for all at all ages [Internet]. New York: United Nations; [cited 2025 Apr 2]. Available from: https://sdgs.un.org/goals/goal3#targets_and_indicators.
6. World Health Organization (WHO). Implementing the global health sector strategies on HIV, viral hepatitis and sexually transmitted infections, 2022–2030: report on progress and gaps 2024 [Internet]. Geneva: World Health Organization; 2024 [cited 2025 Apr 2]. Available from: https://iris.who.int/bitstream/handle/10665/376814/9789240094925-eng.pdf
7. Groseclose SL, Buckeridge DL. Public health surveillance systems: recent advances in their use and evaluation. Annu Rev Public Health. 2017;38:57–79.
8. Jia P, Liu S, Yang S. Innovations in public health surveillance for emerging infections. Annu Rev Public Health. 2023;44:55–74.
9. Birkhead GS, Klompas M, Shah NR. Uses of electronic health records for public health surveillance to advance public health. Annual review of public health. 2015 Mar 18;36(1):345-59.

Annex 1. Questionnaire

Mapping surveillance systems for HIV/AIDS in the European region

Welcome to the survey on mapping surveillance systems for HIV/AIDS in the European region.The European Centre for Disease Prevention and Control (ECDC) and the WHO Regional Office for Europe are collaborating to characterize and map existing surveillance systems for HIV/AIDS within the European region.Your responses will help identify key components, methodologies, and data sources utilized in current HIV surveillance systems. Additionally, the goal is to pinpoint areas of improvement within these surveillance systems.Please note that this survey is not anonymous as we aim to understand the profile of respondents. However, participant information will be securely collected and stored.The data will be hosted by ECDC (the data custodian) and processed in accordance with the EU General Data Protection Regulation.The survey takes approximately 30 minutes to complete.If you have any concerns about this questionnaire, you can contact Juliana.reyes@ecdc.europa.eu and kuchukhidzeg@who.int.Thank you!

1. Country

- ◯ Austria
- ◯ Albania
- ◯ Andorra
- ◯ Armenia
- ◯ Azerbaijan
- ◯ Belarus
- ◯ Belgium
- ◯ Bosnia and Herzegovina
- ◯ Bulgaria
- ◯ Croatia
- ◯ Cyprus
- ◯ Czechia
- ◯ Denmark
- ◯ Estonia
- ◯ Finland
- ◯ France
- ◯ Georgia
- ◯ Germany
- ◯ Greece
- ◯ Hungary
- ◯ Iceland
- ◯ Ireland
- ◯ Israel
- ◯ Italy
- ◯ Kazakhstan
- ◯ Kosovo
- ◯ Kyrgyzstan
- ◯ Latvia
- ◯ Liechtenstein
- ◯ Lithuania
- ◯ Luxembourg
- ◯ Malta
- ◯ Moldova
- ◯ Monaco
- ◯ Montenegro
- ◯ Netherlands
- ◯ North Macedonia
- ◯ Norway
- ◯ Poland
- ◯ Portugal
- ◯ Romania
- ◯ Russian Federation
- ◯ San Marino
- ◯ Serbia
- ◯ Slovakia
- ◯ Slovenia
- ◯ Spain
- ◯ Sweden
- ◯ Switzerland
- ◯ Tajikistan
- ◯ Turkey
- ◯ Turkmenistan
- ◯ Ukraine
- ◯ United Kingdom
- ◯ Uzbekistan

2. Organisation _____

3. Name of the person completing the survey _____

4. Role in the surveillance system _____

Section 1. Objetives of the Surveillance system

Definitions: Surveillance System = for the purposes of this questionnaire this refers to a combination of the following aspects:

- All persons who are involved in the surveillance system (including: data collectors (such as clinicians and laboratories), persons in districts and or regions, network coordinator of the surveillance system, etc.)
- All data produced by the surveillance system
- Means of working of the surveillance system (financial means, communication system, etc.)

1.1. How is the HIV surveillance system in your country coordinated?	◯ National network = HIV surveillance is coordinated by national authorities in the country. Decisions about the surveillance system are national. ◯ Regional network = HIV surveillance is coordinated by regional authorities. Decisions about the surveillance system are regional. ◯ Mixed = HIV surveillance is coordinated by regional authorities, but the final decisions about the surveillance system are national. ◯ Other
If other, please explain	_____
1.2. Does the HIV surveillance system in your country have defined objectives?	◯ Yes ◯ No ◯ Don't know
1.3. What are the objectives of HIV surveillance? Please upload a document outlining them.	
1.4. In your view, are the current objectives in accordance with the current context and needs for information about HIV in the country?	◯ The objectives are still in accordance with the current context and needs for information about HIV ◯ The objectives are still in accordance with the current context and needs for information about HIV but with minor deficiencies. ◯ The objectives are in accordance with the current context and needs for information about HIV but there are major deficiencies. ◯ The objectives are not in accordance with the current context and needs for information about HIV.
1.5. Are you considering or planning to update your HIV surveillance objectives?	◯ Yes ◯ No ◯ Don't know

Section 2. Central/National coordination	
2.1. How many Epidemiologists are currently engaged in the surveillance system, including both regional and national levels? This count should encompass all staff members working full-time equivalents specifically dedicated to HIV surveillance.	_____
2.2. What is the count of technicians (people engaged in data collection, data completeness, and/or data entry) participating in the surveillance system, encompassing both regional and national levels? This includes the number of staff working full-time equivalents dedicated to HIV-related tasks.	_____
2.3. What is the number of Data Managers, including both regional and national levels, who are involved in the surveillance system (number of staff who work in full time equivalents focused on HIV)	_____
2.4. What is the number of Modellers who are involved in the surveillance system (number of staff who work in full time equivalents focused on HIV)	_____
2.5. How do you assess the adequacy of the human resources within the centralized team or organization responsible for overseeing the entirety of the HIV surveillance system?	◯ Very sufficient ◯ Just sufficient ◯ Barely sufficient ◯ Not sufficient
2.6. Is there a centralized team or organization responsible for overseeing the entirety of the HIV surveillance system?	◯ Yes ◯ No ◯ Don't know
2.7. What activities are conducted by the centralized team at national level with respect to HIV surveillance? You can select more than one answer	☐ Data management ☐ Data validation ☐ Data analysis ☐ Modelling (ie generating incidence estimates, or PLHIV estimates) ☐ Communication of results ☐ Other
if other, please explain	_____
2.8. Does the centralized team have financial means that are considered as sufficient and adapted for the tasks assigned?	◯ Yes ◯ No and deficiencies are Minor = Deficiencies generate a constraint on the structure but does not interfere with conduct of surveillance activities ◯ No and deficiencies are Medium = Deficiencies create a constraint that interferes with the conduct of surveillance activities ◯ No and deficiencies are Major = Deficiencies create a constraint that severely limits the conduct of surveillance activities

Section 3. Steering Committee or Equivalent: This entity plays a pivotal role in defining the orientations and objectives of the network, as well as making strategic decisions. It encompasses the main decision-making bodies involved in surveillance. Depending on the network's size, the steering committee may be integrated with the centralized team at national level.	
3.1. Does the HIV surveillance system have a steering committee in place?	◯ Yes ◯ No ◯ Don't know
3.2. Does the steering committee, or its equivalent, collaborate with a centralized team at the national level tasked with guiding the existing HIV surveillance system?	◯ Yes ◯ No ◯ Don't know
3.3. Who is a part of the steering committee (or equivalent)? You can select more than one answer	☐ Epidemiologist (s) from national level ☐ Epidemiologist(s) from regional/sub-national level ☐ laboratories ☐ Government ministries (departments) ☐ Patients' association ☐ Civil society other than patients' associations ☐ Clinicians ☐ Other
if other, please explain	_____
3.4. Is HIV surveillance formalized within national legislation (or through official national regulation)?	◯ Yes ◯ No ◯ Don't know
3.5. Is there a document or set of documents that comprehensively defines the roles for various partners within the surveillance network, taking into account multiple actors and legislation?	◯ Yes ◯ No ◯ Don't know
3.6. How much of the country does your national HIV surveillance system cover?	◯ all country ◯ 75% of the total population ◯ 50% of the total population ◯ 25% or less of the total population

Section 4. Intermediary unit or regional surveillance systems = Represent the intermediate level between data collectors and centralized team at national level. Their aim is to coordinate field activities and to validate and eventually correct the collected data before sending them to thecentralized team at national levelt. It's possible to have different levels of intermediary unit (example : provincial level and district level)

4.1. Are there intermediary or regional units in your country's HIV surveillance system?	◯ Yes ◯ No ◯ Don't know
4.2. How many intermediary or regional units are there? A count of zero [0] signifies the absence of intermediary regional units	_____
4.3. What activities are conducted by the intermediary units at regional level with respect to HIV surveillance? You can select more than one answer	☐ Data collection ☐ Data management ☐ Data validation ☐ Data analysis ☐ Modelling (ie generating incidence estimates, or PLHIV estimates) ☐ Communication of results ☐ Other
if other, please explain	_____
4.4. Are there differences between administrative areas/regions in the way that HIV reporting occurs? (example: a province uses a different form for transmission of HIV surveillance data)	◯ Yes ◯ No ◯ Don't know
4.5. The impact of these differences is:	◯ Minor = generates a constraint on the structure (additional work for data entry and analysis etc.) but does not interfere with the conduct of surveillance activities ◯ Medium = creates a constraint that interferes with the conduct of surveillance activities (some data are unavailable etc) ◯ Major = creates a constraint that severely limits the conduct of surveillance activities (lot of data are lost or unavailable
4.6. Are any harmonisation procedures in place to improve differences in reporting practices across regions?	◯ Yes ◯ No ◯ Don't know
4.7. Which activities are being considered into this harmonizing procedure? Please explain	_____

Section 5. Reporting procedure	
5.1. Are there sufficient resources, encompassing both financial and technical aspects such as data collectors or established databases, to facilitate the process of reporting new HIV diagnoses effectively by clinicians and/or laboratories?	◯ Yes ◯ No ◯ Don't know
5.2. If you believe that the current resources are insufficient to support clinicians and/or laboratories in effectively reporting new HIV diagnoses, could you please provide an explanation for your assessment?	_____
5.3. What resources are available to assist clinicians and/or laboratories in managing the data effectively? You can select more than one answer	☐ Case notification forms ☐ Database access ☐ Dashboard ☐ Other
if other, please explain	_____
5.4. Is there a network fee or any other incentive paid to clinicians/laboratories when they report a new case?	◯ Yes ◯ No ◯ Don't know
5.5. If yes, please describe	_____
5.6. What is the main barriers to clinician reporting newly diagnosed HIV cases to the surveillance system? You can select more than one answer	☐ Time constraints ☐ Privacy concerns ☐ Complexity of reporting process ☐ Lack of training ☐ Inadequate reporting infrastructure ☐ Fear of stigma ☐ Other ☐ Not Applicable
if other, please explain	_____
5.7. Do laboratories report newly diagnosed HIV cases to the HIV surveillance system in your country?	◯ Yes ◯ No ◯ Don't know
5.8. What are the main barriers to laboratories reporting newly diagnosed HIV cases to the surveillance system?	☐ Time constraints ☐ Privacy concerns ☐ Complexity of reporting process ☐ Lack of training ☐ Inadequate reporting infrastructure ☐ Fear of stigma ☐ Other
if other, please explain	_____

5.9. What percentage of laboratory data can be linked with epidemiological data?	◯ Less than 25% ◯ 25% - 50% ◯ 51% - 75% ◯ More than 75% ◯ Not sure/Don't know
5.10. How accurately can you estimate the extent of under-reporting by laboratories, ranging from 0% (no under-reporting) to 100%?	0 50 100 *(Place a mark on the scale above)*
5.11. What are the primary barriers to linking laboratory data with epidemiological data? You can select more than one answer	☐ Us of different identification numbers that preclude linking between data systems ☐ Lack of interoperability between systems ☐ Privacy concerns ☐ Limited resources for data integration ☐ Legal or regulatory restrictions ☐ Technical challenges in data matching ☐ Insufficient training or expertise ☐ Lack of standardized protocols ☐ Data quality issues ☐ Institutional or organizational barriers ☐ Other
5.12. How is the reporting from the laboratories to the surveillance system?	◯ Reporting is automated. ◯ Reporting requires manual entry by laboratory staff. ◯ Reporting is semi-automated, with some manual input required. ◯ Reporting methods vary depending on the laborator ◯ Not sure/I don't know.
5.13. What types of unique identifiers do laboratories typically use to identify individuals?	_____
5.14. Is it possible to identify two positive tests belonging to the same individual?	◯ Yes ◯ No ◯ Don't know
5.15. How are laboratory results typically transmitted to the HIV surveillance system?	◯ Secure electronic data transfer through dedicated data systems ◯ Via email. ◯ Through manual data entry into surveillance databases. ◯ Through automated interfaces between laboratory and surveillance systems. ◯ By submitting paper forms or reports. ◯ Other
5.16. Is there a documented surveillance protocol for reporting cases used in your country?	◯ Yes ◯ No ◯ Don't know
5.17. Is the protocol up to date and in accordance with the current HIV context?	◯ Yes ◯ No ◯ Don't know

5.18. Does your country use the ECDC case definition for HIV? Adults, adolescents and children aged ≥ 18 months At least one of the following three: - Positive result of a HIV screening antibody test or a combined screening test (HIV antibody and HIV p24 antigen) confirmed by a more specific antibody test (for example, Western blot); - Positive result of 2 EIA antibody test confirmed by a positive result of a further EIA test; - Positive results on two separate specimens from at least one of the following three: - Detection of HIV nucleic acid (HIV-RNA, HIV-DNA); - Demonstration of HIV by HIV p24 antigen test, including neutralisation assay; - Isolation of HIV. Children aged < 18 months Positive results on two separate specimens (excluding cord blood) from at least one of the following three: - Isolation of HIV; - Detection of HIV nucleic acid (HIV-RNA, HIV-DNA); - Demonstration of HIV by HIV p24 antigen test, including neutralisation assay in a child ≥ 1 month of age.	◯ Yes ◯ No ◯ Don't know
If your country employs a case definition different to the ECDC or WHO criteria, please upload it here.	
5.19. Is there a standardized notification form available for clinicians?	◯ Yes ◯ No ◯ Don't know ◯ Not Applicable
5.20. Is there a standardized notification form available for laboratories?	◯ Yes ◯ No ◯ Don't know
5.21. Does a guideline exist that specifies a standard timeframe for the maximum transmission time of results from clinicians to the National Surveillance system?	◯ Yes ◯ No ◯ Don't know ◯ Not Applicable
5.22. What time is stipulated in the guideline for transmitting results from clinicians to the National Surveillance system? Mean/median days	_____
5.23. What is the current mean/median notification delay from clinicians to the National Surveillance system in your country? State the time in days , where zero [0] means no delay	_____
5.24. How would you estimate the level of under-reporting, on a scale from 1 to 100%, in general? A score of 0 indicates no underreporting within your country.	0 50 100 *(Place a mark on the scale above)*

5.25. Does the degree of under-reporting vary between geographical regions?	◯ Yes ◯ No ◯ Don't know
if yes, please explain	_____
5.26. How accurately can you gauge the extent of under-reporting by clinicians, ranging from 0% (no under-reporting) to 100%?	0 50 100 *(Place a mark on the scale above)*
5.27. How accurately can you gauge the extent of under-reporting by regional authorities, ranging from 0% (no under-reporting) to 100%?	0 50 100 *(Place a mark on the scale above)*
5.28. How does your country assess or estimate the proportion of under-reporting?	◯ We don't assess or estimate the proportion of under-reporting ◯ Through statistical modeling and extrapolation based on known cases and surveillance data. ◯ By conducting seroprevalence studies to estimate the actual number of cases in the population. ◯ Using capture-recapture methods, which involve comparing multiple data sources to estimate the number of cases missed by each source. ◯ Through surveys or interviews with healthcare providers to gauge their awareness of underreporting and factors influencing reporting practices. ◯ By analyzing trends in healthcare-seeking behavior and comparing them with reported case counts. ◯ Other
5.29. Is the surveillance system able to identify the following key populations? You may select more than one option.	☐ Men who have sex with men ☐ People who have injected drugs ☐ People who have engaged in sex work ☐ Transgender ☐ People who have been in prison ☐ People born abroad ☐ Other
if other, please explain	_____

Section 6. Data collection and management	
6.1. Is there a structured data management procedure in place, encompassing data validation and secure storage within databases?	◯ Yes ◯ No ◯ Don't know
If yes, please provide a concise explanation of the data management procedure that your country has implemented	_____
6.2. Does the national HIV surveillance system have a centralised database?	◯ Yes ◯ No ◯ Don't know
6.3. What are the limiting factors of this database, if any?	_____
6.4. How are newly diagnosed HIV cases that have been notified collected and aggregated at the national level?	◯ Using electronic reporting systems that automatically collect and transmit data to a centralized database. ◯ Through paper-based reporting forms submitted by healthcare facilities to regional or national health departments. ◯ Other
if other, please explain	_____
6.5. Are the financial means to manage and maintain the database are considered as sufficient?	◯ Yes ◯ No and Minor deficiencies : deficiencies generate a constraint on the structure but do not interfere with the conduct of surveillance activities ◯ No and Medium deficiencies : deficiencies create a constraint that interferes with the conduct of surveillance activities ◯ No and Major deficiencies : deficiencies create a constraint that severely limits the conduct of surveillance activities

6.6. What processes are employed for validating HIV surveillance data provided by clinicians and/or laboratories? You may choose multiple options.	☐ 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.
6.7. What is the response rate to validation queries (from those reporting data)? A score of 0 indicates no validation process	0 50 100 *(Place a mark on the scale above)*
6.8. What are the limiting factors or barriers for data validation?	_____
6.9. What are the limiting factors or barriers for data entry ?	_____
6.10. What is the number of staff allocated to data analysis?	_____
6.11. What are the limiting factors or barriers for data analysis?	_____
6.12. What measures, if any, are taken to address missing data among reported cases? This could involve methods such as weighting approaches during statistical analysis or supplementing the information through additional data sources.	_____
6.13. What specific identifier within the surveillance system is employed to identify individuals newly diagnosed?	_____
6.14. Can this identifier be used to link back to personal information from other sources?	◯ Yes ◯ No ◯ Don't know
6.15. Can the surveillance system effectively identify and eliminate duplicate cases?	◯ Yes ◯ No ◯ Don't know

If yes, which the method is used for eliminating duplicate cases?	_____
6.16. Can the system effectively recognize individuals with a previous positive diagnosis?	◯ Yes ◯ No ◯ Don't know
If yes, are cases considered previous positive diagnoses analysed separately from newly diagnosed ones?	_____
If not, what barriers are there to identify previous positive cases separately from the newly diagnosed cases?	_____
6.17. Is information regarding AIDS diagnoses (occurring downstream, after HIV notification) collected in the surveillance system?	◯ Yes ◯ No ◯ Don't know
If not, what barriers are there to report AIDS diagnoses occurring downstream, after HIV notification?	_____
6.18. Is information regarding date of death collected for cases that have been reported in the surveillance system?	◯ Yes ◯ No ◯ Don't know
6.19. Is information regarding cause of death linked for cases that have been reported in the surveillance system?	◯ Yes ◯ No ◯ Don't know
If yes, which are the sources of information used to retrieve mortality data?	◯ Health Records and Medical Facilities: linkage with health records from hospitals, clinics, and other medical facilities. ◯ Mortality Registries at regional level: linkage with regional mortality registries or databases maintained by health departments or other government agencies. ◯ National Death Registries: linkage with national death registries or vital statistics systems. ◯ Manual notification systems: individually searching various data sources to determine vital status. ◯ [5] Other
6.20. How frequently does the surveillance system update information pertaining to vital (ie death) status?	◯ Never ◯ Every year ◯ Every two years ◯ Every five years ◯ There is not periodicity

If not, which barriers exist in updating the vital (ie death) status of individuals who have been reported in the HIV surveillance system?	☐ Limited Resources: Insufficient human, financial, or technological resources. ☐ Lack of Interoperability: Systems do not easily communicate with each other impede the seamless flow of vital status updates. ☐ Mortality Reporting Delays: Delays in receiving official death certificates or mortality reports from relevant authorities. ☐ Legal and Regulatory Constraints: Compliance with legal and regulatory frameworks pose challenges in obtaining and updating vital status information. ☐ Limited Technology Adoption: The absence or slow adoption of advanced technologies for data management and reporting hinder real-time updates. ☐ Data Security Concerns: Ensuring the security of sensitive health information. ☐ Under-reporting (if manual notification system) ☐ Other

Section 7. Communication of results

7.1. Are regular reports and/or scientific articles about results of surveillance released by the surveillance system?	◯ Yes ◯ No ◯ Don't know
7.2. How often is data published? In months	_____
7.3. Who are targets of the communication of surveillance results and data? You may select more than one option.	☐ General public ☐ Neighbouring countries ☐ Network members ☐ Clinicians ☐ International organisations ☐ Private and public national partners ☐ Civil society ☐ Politicians ☐ Laboratories ☐ Researchers ☐ Key populations ☐ other
7.4. What are means used to communicate the surveillance results? You could check more than one answer	☐ dashboards ☐ epi bulletins or reports ☐ scientific articles ☐ social media ☐ Website ☐ Other

Section 8. Evaluation of the surveillance system	
8.1. Has an internal evaluation of the HIV surveillance system previously been carried out?	◯ Yes ◯ No ◯ Don't know
if yes, what method was used?	_____
if yes, when was performed for the last time?	_____
What attributes were evaluated?	_____
8.2. Has an external evaluation of the HIV surveillance system previously been carried out?	◯ Yes ◯ No ◯ Don't know
if yes, what method was used?	_____
if yes, when was performed for the last time?	_____
What attributes were evaluated?	_____

Annex 2. Extra tables from the HIV surveillance system mapping

Annex Table 1. EU/EEA country survey of HIV surveillance systems: data management procedures implemented to handle HIV surveillance data by country, 2024

Country	Data management procedures implemented to handle HIV surveillance data
Austria	We use study cohort data. A study-cohort internal management process is in place.
Belgium	Deduplication, generation of queries data providers in case of data quality issues.
Croatia	In Croatia, there is a centralised system of treatment of people with HIV infection and AIDS (in one clinical hospital in the capital city) and the report/notification of HIV/AIDS disease is submitted by the institution that provides treatment services by directly entering the data in an electronic online database - separate domain of the National Information System - in the national HIV/AIDS registry. The Internet interface for data entry is an online application within the National Information System (NAJS). The security of the system depends not only on the technical settings, the technologies used and the access administration, but also on the daily business processes that must be harmonised with the needs of standards for preserving the privacy of subjects whose data is recorded. The domains within NAJS are integrated with each other in such a way that they maintain defined procedures of employees who have the authority to work on parts of the system, and only persons who are authorised to work in that system have access (access with username and password). Entry to the database is secured according to modern IT security standards and additional security (SSL protocol, double authentication for user verification to work in the application, search or access to personal data requires additional authentication, anonymized data export with limited access). All employees who work on data entry, validation and analysis are educated about the obligation to protect personal data.
Cyprus	
Czechia	
Denmark	We store data from the surveillance system in a database based in the SSI, within the Ministry of Health.
Estonia	The data is stored in the Estonian Communicable Diseases Register. The data is overseen and corrected by its administrator. The possibilities of the registry are limited, the data are therefore downloaded and managed in Excel files.
Finland	
France	The majority of data (95%) are sent via the online declaration system. The remaining 5% arrive on paper forms and are entered at the national level. Repeat declarations are identified based on an identical anonymisation code. The system also identified individuals with codes referring to near-identical personal information, which the technicians then compare manually. The technicians classify declarations into patient folders based on their IDs. If data is missing or incoherent, a request is sent to the declaring physician/laboratorian. If only one form received (physician or laboratorian), a reminder is sent to the other potential declarant. Every quarter, a raw data file is produced from the database exports, at which point additional automated checks are done for errors and these are corrected if possible.
Germany	Matching algorithm; de-duplication; plausibility check.
Greece	
Ireland	Data are collected via Computerised Infectious Disease Reporting System (CIDR.)
Italy	Check of double reporting, correct errors, variables inconsistency or discrepancy, missing data.
Liechtenstein	Data are managed in the Swiss Data management System for Infectious Diseases and validated there. In addition, there is also a data management procedure done by preparing and uploading the HIV data to TESSy. HIV and AIDS data are stored on a secure drive internally (it meets the data protection criteria) in the Office of Public Health.
Lithuania	A centralised system—the National Communicable Diseases and Pathogens Information System (ULSVIS)—collects, processes, analyses, and stores data on communicable disease cases, pathogens, and other epidemiologically relevant information. This system supports the early detection of infectious diseases and outbreaks, facilitates timely and appropriate responses, and strengthens the overall management of public health threats. HIV case data are managed within a dedicated module of the system. A portion of these data is automatically transferred from the Electronic Health Services and Cooperation Infrastructure Information System (ESPBI IS), while the remainder is submitted in paper format and entered manually via an online interface. System security is maintained through a combination of technical safeguards, applied technologies, and access controls, along with daily operational procedures aligned with personal data protection and privacy regulations. By 2028, full automation of all processes and data reporting—eliminating paper submissions—is planned.
Luxembourg	Data are sent by labs via xml/HDA7 to Agence e-sante who makes an integrity check and transfers date to our data base, which can only be accessed via double authentication. Clinical data are collected and stored within the hospital. Data are validated by the national authority.
Malta	
Netherlands	Protocolised data collection with validation during and after data entry.
Norway	Positive results are reported electronically from the laboratories and form the basis for new cases in the surveillance system. Identity and information on personal data is retrieved and quality assured from the central population registry. Epidemiological information is reported by the clinician and information is combined with the laboratory information in a common database.
Poland	All HIV cases diagnosed by clinicians and/or laboratories are reported to the local sanitary stations. Data are filled by clinicians/laboratory and send on paper forms to sanitary inspections, after this they are reported to central database - by electronic system. After first verification all data are sent by electronic system to the central database. Access to this database is after authorisation only for authorized employees of NIPH NIH-NRI. Secondly, after the next data verification and control process, anonymous data are analysed, and assessment of epidemiological situation is presented to public information. In 2025 we planning introduce electronical reports only.
Portugal	Data collection: Electronic web-based reporting system (Clinicians and Laboratories); Validation by Public Health officer/Health Authority; Database Validation and registration. Secure storage – Ministry of Health servers.
Romania	Based on the Technical Norms of the National Health Programmes (uploaded in the first page).
Slovenia	

Country	Data management procedures implemented to handle HIV surveillance data
Spain	Once a year, regional surveillance departments send databases of new HIV diagnoses and AIDS cases separately, to the national level through a secure exchange channel. At the national level, data quality control is performed, and the regional databases are aggregated to create the national databases.
Sweden	Secured database system with incorporated data validation.

CIDR: Computerised Infectious Disease Reporting System; xml/HDA7: extensible Markup Language /Health data A7;; NAJS: Nacionalni Automatizirani Jedinstveni Sustav from Croatia (English: National Automated Integrated System); NIPH-NIH-NRI: National Institute of Public Health – National Institute of Hygiene – National Research Institute; SSI: Statens Serum Institut (English: State Serum Institute); TESSy: The European Surveillance System.

Annex Table 2. EU/EEA country survey of HIV surveillance systems: unique identifiers utilised across HIV surveillance systems and reporting laboratories in each country, 2024

Country	Surveillance systems	Laboratories
Austria	In cohort study: social health insurance number	
Belgium	Pseudonymised national register number	National Registry Number (pseudonymised before sending to the national surveillance)
Croatia	Personal identification number (OIB)	
Cyprus	N/A	
Czechia	ID number, name	ID number
Denmark	CPR number	CPR (national identification number)
Estonia	Personal identification code	Personal identification code
Finland	Social security number	Social security number
France	A pseudonymized ID that has been used since the beginning of the surveillance system based on patient information; is generated at the point of declaration	Pseudonymous ID generated based on patient information
Germany	Alphanumeric HIV code; will be changed within this year to electronic system and electronic ID	Alphanumeric code of name
Greece		
Ireland	Names are not available to surveillance staff at national surveillance level, DOB, Specimen ID	Names are not available to surveillance staff at national surveillance level, DOB, Specimen Number, Clinic ID
Italy	Identification anonymous code	
Liechtenstein	Date of diagnosis	They currently use Lab-IDs and an encrypted personal information.
Lithuania	ID-number, date of diagnosis and free text	
Luxembourg	Social security number	Social security number
Malta	GU number, ID number	GU number, ID Number
Netherlands	Patient number/surveillance code	
Norway	National identity number	National identity numbers
Poland	DoB, name/surname/ initials and gender are considered sufficient for duplicates identification. Legally reports without identifier are allowed (gender, year of birth, residence are required)	Name, surname, DOB, insurance number
Portugal	National Health Service user number. This is related to the database itself where we store the data. Both clinical notification and lab notification are made with the UID	National Health Service user number
Romania	Report between the data released by the clinicians and laboratories and the surveillance system	Code/name
Slovenia		
Spain	Depends on regional system	
Sweden	ID-number, date of diagnosis and free text	Personal identity number or reserve number (only physicians and lab know the complete ID number)

CPR: Det Centrale Personregister (English: The Central Person Register); DOB: Date of Birth; GU: Genitourinary number; ID: Identification number; OIB: Osobni identifikacijski broj (English: Personal Identification Number); UID; Número de Utente do SNS (User Number for the National Health Service).

Annex Table 3. EU/EEA country survey of HIV surveillance systems: measures used to address missing data among reported cases by country, 2024

Country	Measures used to address missing data among reported cases
Austria	We use the ECDC tool for the HIV estimates
Belgium	Multiple imputation
Croatia	There is centralised system of treatment of people with HIV infection and AIDS (in one clinical hospital in the capital city) and the report/notification of HIV/AIDS disease is submitted by that institution that provides treatment services by directly entering the data in an electronic online database - separate domain of the National Information System - in the national HIV/AIDS registry. Therefore, all questions and problems related to correcting or supplementing data are carried out in direct communication and cooperation with employees who carry out data entry.
Cyprus	N/A
Czechia	
Denmark	Modelling
Estonia	Sometimes clinicians are contacted.
Finland	Automatic reminders from the registry, training sessions
France	If essential, queries back to declarant; reminders to clinician (if only laboratory form received) or laboratorian (if only clinician form received); multiple imputation
Germany	Supplementary information is used from secondary data sources, pharmacy prescription data, health insurance
Greece	
Ireland	Follow up of inconsistencies on enhanced forms with clinicians/laboratories
Italy	Reaching regional contacts to fill the gaps
Liechtenstein	
Lithuania	
Luxembourg	We contact the doctors for supplementary information.
Malta	
Netherlands	
Norway	Clinicians are reminded to report for cases missing epidemiological information.
Portugal	An information request is sent to reporting clinicians when data is missing
Romania	Additional information request
Slovenia	
Spain	None
Sweden	

European Centre forDisease Prevention and Control (ECDC)

Gustav III:s Boulevard 40
16973 Solna, Sweden

Tel. +46 858 60 10 00
ECDC.info@ecdc.europa.eu

www.ecdc.europa.eu

Publications Office
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