

HUMAN IMMUNODEFICIENCY VIRUS (HIV) AND ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS) CASE REPORTING IN THE WORLD HEALTH ORGANIZATION EUROPEAN REGION IN 2006

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This article presents information on HIV and AIDS case reporting systems as part of a survey on HIV/AIDS surveillance practices in the World Health Organization (WHO) European Region. A standardised questionnaire was sent to the 53 national correspondents of the European Centre for the Epidemiological Monitoring of AIDS (EuroHIV). The HIV and AIDS case reporting section of the questionnaire comprised four parts: data collection system, HIV/AIDS case definition for surveillance, variables collected, and evaluation of surveillance systems). Individual-based data collection systems for HIV case reports have been implemented in 43 of 44 countries in the WHO European Region and for AIDS case reports in all the countries. For HIV case reports, a coded identifier is used in 28 countries, and full names are used in 11 countries. The European AIDS case definition has been adopted in 35 countries (80%). Information on molecular epidemiology is available in 30 countries, and HIV drug resistance is monitored in 11 countries. HIV/AIDS case reporting systems have been evaluated for under-reporting in 17 countries and for completeness in 11 countries. This article outlines the future needs for HIV/AIDS surveillance and presents recommendations on how to improve data comparability across European countries in the WHO region.

Introduction

Originally, the focus of surveillance rested on reporting of AIDS cases, which was the main tool to monitor the epidemic trends but, with the introduction and widespread use of highly active anti-retroviral treatment (HAART), the number of AIDS diagnoses no longer reflects the underlying trends in the HIV epidemic satisfactorily. Hence, reporting of HIV diagnoses has progressively replaced AIDS case reporting as a surveillance instrument for monitoring the HIV epidemic in Europe.

Recommendations for HIV surveillance in Europe were published in 1998 based on the results of a survey that was conducted by EuroHIV among the group of experts and national coordinators from the countries of the World Health Organization (WHO) European Region [1]. The recommendations underlined the need for information regarding national reporting systems in order to facilitate international comparisons of HIV and AIDS data.

Since 1998, new treatment regimens have been introduced and the laboratory technologies have improved considerably. Therefore the detection of new patterns of resistance to antiretroviral treatments presents a number of challenges and opportunities in the context of monitoring HIV resistance in Europe.

A new survey on HIV and AIDS surveillance practices was conducted by EuroHIV in 2006 [2], which had the same aim as the original one conducted in 1998. This article presents the collected data regarding HIV and AIDS case reporting in the 53 member states of the WHO European Region

Aim and objectives of the survey

The survey on HIV and AIDS surveillance aimed to assess national surveillance systems for HIV/AIDS in order to make recommendations on HIV/AIDS surveillance across Europe.

The specific objectives of the survey as presented in this paper were:

- to determine HIV/AIDS surveillance practices across Europe, with special emphasis on HIV/AIDS case reporting and HIV/AIDS mortality surveillance,
- to develop technical recommendations and guidelines in order to improve data comparability across Europe,
- to provide baseline data needed to ascertain the feasibility of HIV/AIDS surveillance in Europe and coordinate its development in the future.

Methods

The questionnaire

The survey was conducted using a standardised questionnaire that was first tested in a pilot round among EuroHIV steering group members. The questionnaire was divided into the following four sections:

- HIV and AIDS case reporting,
- HIV testing practices,
- other surveillance practices (HIV incidence and prevalence estimates),
- mortality data.

The results of the first section of the questionnaire, on HIV and AIDS case reporting, are presented in this article. This section was made up of five sub-sections further described in the EuroHIV report [2].

Data collection and analysis

The questionnaire was sent out at the end of April 2006 to the EuroHIV national correspondents in all 53 countries in the WHO European Region. A Russian translation of the questionnaire was also available. Reminders were sent after one month and three months, and further contacts (email, fax and telephone) were made to improve the response. In December 2006, the questionnaire was also sent to WHO contact points from five countries. Data collection for the survey was completed in February 2007.

In this article, results will be presented with a particular focus on the following areas of HIV and AIDS surveillance:

- data collection system,
- HIV/AIDS case definition for surveillance,
- variables collected,
- evaluation of surveillance systems.

Results

The questionnaire was returned by 44 of the 53 countries (overall response rate of 83%): 26 of the 27 European Union (EU) countries (96%; non-respondent: Cyprus) and 18 non-EU countries (Andorra, Armenia, Azerbaijan, Belarus, Bosnia and Herzegovina, Croatia, Georgia, Iceland, Israel, Kazakhstan, Kyrgyzstan, Norway, Republic of Moldova, Russian Federation, Serbia, Switzerland, Turkey and Ukraine)

Case reporting systems

In 2006, there was an HIV case reporting system in place in 43 of the 44 responding countries (98%), the exception being Austria where HIV surveillance was operated through a cohort study (Table 1). In 37 countries (86%), data were collected directly at the national level (no regional intermediate for data collection). Individual data were collected by 40 countries (93%). Reporting was done by both laboratories and physicians in almost two-thirds of the countries (27/43), only by laboratories in nine countries and only by physicians (either hospital-based or community-based physicians or both) in six countries.

TABLE 1
Information on data collection system, WHO European Region, 2006

	HIV		AIDS	
	%	(n/N)	%	(n/N)
Case reporting	98%	(43/44)	100%	(44/44)
National level	86%	(37/43)	93%	(41/44)
Individual data	93%	(40/43)	95%	(42/44)
Reporting by:				
Laboratories only	21%	(9/43)	2%	(1/44)
Physicians only	14%	(6/43)	73%	(32/44)
Both	63%	(27/43)	18%	(8/44)

n: number of countries with positive answer; N: number of participating countries

In 2006, there was an AIDS case reporting system in all the countries (Table 1). Data were collected directly at the national level in 41 of 44 countries (93%). Data collection was case-based at national level in 42 countries. AIDS cases were reported solely by physicians in 32 (73%) countries (in 11 of which reporting was done solely by hospital physicians), solely by laboratories in one country, and by both laboratories and physicians in eight countries.

HIV and AIDS case reports were compiled in one combined database in 30 of 43 countries (70%) and, for seven additional countries where HIV and AIDS case reporting were in different databases, there was a possibility of linking between the HIV and the AIDS databases. Thus, of the 43 countries, the minority (six) were unable to link HIV and AIDS databases (Denmark, Iceland, Italy, Malta, Norway and Spain).

HIV case reporting HIV testing algorithms

Figure 1 shows the various HIV testing algorithms for surveillance purposes that are required for the diagnosis and reporting of an HIV case in an adult, an adolescent or a child aged 18 months or older. The most commonly used confirmatory tests were immunoblot (including Western Blot; used in 34 countries), or a second enzyme immunoassay (EIA; used in 17 countries). Four countries (Armenia, Kazakhstan, Portugal and Romania) required three positive tests for the diagnosis/reporting of HIV cases, including two EIA. A single positive test, i.e. detection of nucleic acid by PCR, p24 antigen testing or viral culture, was accepted in 10 countries although the number of HIV cases detected with one of these tests represented less than 10% of the cases reported in these countries in 2005.

Case identification

Forty of the 43 countries provided information on the case identifier in order to detect duplicate reports (information not reported for Austria, Belarus, Kazakhstan and Spain): Twenty-eight countries (70%) used a coded identifier based on the patient's name or part of the name (17 countries) or did not include the patient's name (11 countries). Twelve countries (30%) used full names (Figure 2).

Description of the cases and transmission categories

Information on sex and age was collected in all countries (see Table 2); data on ethnicity or place of birth (or both) were collected

FIGURE 1
HIV testing algorithms used in the countries in the WHO European Region, 2006

First screening test	Confirmation test	Number of countries
ELISA	No test	2
	2nd ELISA	17
	Western Blot	34
	Immunoblot	13
	Other	5
PCR	2nd + 3rd ELISA or other test	4
	P24 antigen	10
	Viral culture	

in 34 countries (79%) and are planned to be collected in Bulgaria (not collected in Belarus, Estonia, Finland, Hungary, Poland, Republic of Moldova, Switzerland and Ukraine).

Information on the transmission category was collected by 40 countries, and on current drug injection status by 24 countries.

Clinical and virological characteristics

32 countries recorded the clinical stage at HIV diagnosis and four countries planned to do so in the near future (Bulgaria, Luxembourg, Republic of Moldova, Russian Federation). The definition used for clinical stage was the 2005 revised WHO clinical staging of HIV and AIDS for adults and adolescents [3] in 10 countries, the 1990 WHO clinical staging of HIV and AIDS for adults and adolescents in five countries, and the 2005 clinical staging system by the United States (US) Centers for disease control and prevention (CDC) in seven countries.

The CD4+ lymphocyte (CD4) count was documented in 21 countries and is planned to be collected in six countries.

Some countries also collected data on molecular biology parameters: 10 countries collected data on HIV type, group and sub-type, four on type and sub-type, three countries collected data on sub-type only and 17 countries on types only. The laboratory methods used to characterise the virus were serological assays (16 countries), PCR (21 countries) and hybridisation (Belarus). Both PCR and serological assays were used in nine countries (Azerbaijan, Bulgaria, Croatia, France, Georgia, Hungary, Kyrgyzstan, Portugal, Sweden).

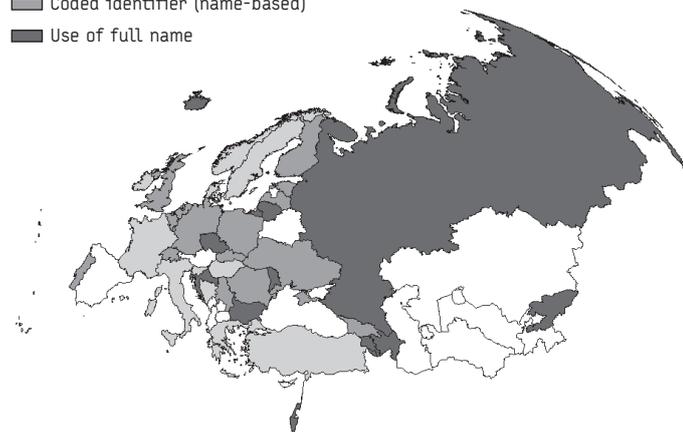
Monitoring death among HIV-infected persons

The HIV database could be linked to vital statistics or death certificate information in 18 countries (seven EU countries). Mortality data for HIV cases were reported in the routine HIV surveillance in 29 countries (66%). Date of death was recorded in all these countries, and in 23 of them also the cause of death. In 27 countries, death was reported by physicians, and in six countries by another source of information. The information collected was "death from any cause" in 13 countries and "death due to HIV infection (HIV infection is the only diagnosis at the time of death)"

FIGURE 2

Case identifiers used for detecting duplicates, WHO European Region, 2006

- No response or missing data
- Coded identifier (not name-based)
- Coded identifier (name-based)
- Use of full name



in 13 other countries. Both types of information (HIV-related and non HIV-related deaths) are collected in Azerbaijan and Portugal.

AIDS case reporting

AIDS case definition

Different AIDS case definitions were used for AIDS case reporting [4]. Most of the countries in the WHO European Region (35, 80%) used the 1993 European AIDS Surveillance Case Definition [5]. Seven countries (Armenia, Belarus, Georgia, Latvia, Romania, Russian Federation and Ukraine) used the US CDC AIDS case definition [6]. Andorra and Belarus reported using the WHO 1994 case definition for AIDS surveillance in adults and adolescents.

The age cut-off for adolescent and adult AIDS surveillance case definitions varied between countries (Figure 3). In the 1993 European AIDS case definition, the age cut-off for adults and adolescents was 13 years and over. However, 17 of the 35 countries using that definition, set the age cut-off for adults and adolescents at 15 years, eight countries at 13 years (which is in accordance with the case definition proposed by the European centre for disease prevention and control (ECDC) [7]), and the 10 remaining countries used another or unknown age cut-off. In countries using the CDC or WHO case definition for AIDS, the age cut-off for adults and adolescents varied between 12 and 15 years.

Description of cases, clinical stage and transmission categories

Information on sex and age was collected in all the countries. Ethnicity or place of birth (or both) were documented in 35 countries (80%) and planned to be recorded in Bulgaria (not collected in Belarus, Estonia, Finland, Hungary, Moldova, Poland, Switzerland and Ukraine).

TABLE 2

Variables collected in the national HIV and AIDS case reporting systems, WHO European Region, 2006

Variables	HIV case reporting (N=43)		AIDS case reporting (N=44)	
	No. of countries	%	No. of countries	%
Sex	43	100%	44	100%
Age	43	100%	44	100%
Ethnicity and/or place of birth	34	79%	35	80%
Date of:				
HIV diagnosis	43	100%	41	93%
HIV report	40	93%	33	75%
AIDS diagnosis			42	95%
AIDS report			42	95%
Clinical stage	32	74%	32	73%
CD4 count	21	49%	26	59%
Transmission group	40	93%	42	95%
IDU status	24	56%	26	59%
ART			27	61%
ARV drug resistance	7	16%	9	20%
Mortality:				
Date of death	29	67%	42	95%
Cause of death	23	53%	33	75%

IDU: injecting drug users; ART: anti-retroviral treatment;

The CD4 count at the time of AIDS diagnosis was obtained in 26 countries (59%) and planned to be recorded in Moldova, Russian Federation and Slovakia.

The transmission category was recorded in 42 countries. Information on current drug injection status was collected by 26 countries.

Antiretroviral therapy (ART) and HIV drug resistance

The AIDS reports in 27 countries noted whether a patient was on ART at the time of AIDS diagnosis, and a further five countries (Belgium, Bulgaria, Estonia, Finland, Russian Federation) plan to start collecting this information in the near future.

Monitoring of resistance to ART was performed in nine countries among reported AIDS cases (and in seven countries among reported HIV-infected cases). Eleven additional countries plan to begin collecting this information within the next two years. The definition used for resistance was the "Stanford algorithm" in four countries, key resistance mutations defined by the International AIDS Society in four other countries, and another definition (not specified) in two countries.

Monitoring of death among AIDS cases

The AIDS database could be linked to vital statistics or death certificate information in 20 countries (nine EU countries). Mortality data on AIDS cases were reported in the routine AIDS cases surveillance system in 42 (95%) countries (all responding countries except Azerbaijan and Croatia). Date of death was recorded in all these countries and cause of death in 33 countries. AIDS death was reported by physicians in 39 countries and by another source of information in six countries. The information collected was "all causes of deaths among people living with AIDS" in 19 countries, "only deaths due to AIDS or AIDS-related illnesses" in 18 countries and "deaths from AIDS-defining illness" in two countries.

National evaluations of HIV and AIDS case surveillance systems

Over half of the countries (25 of 44, 57%) had not evaluated either their HIV or AIDS surveillance systems for under-reporting. Of the 17 countries that had done so, seven had assessed under-

reporting of HIV reports only (i.e. HIV cases that are diagnosed but not reported), three reporting of AIDS only and eight reporting of both surveillance systems. The proportion of under-reporting in a country can be linked to the number of sources of information and can therefore vary widely between countries. For example, the proportion of under-reporting is low in the United Kingdom (UK) and Germany where only a few laboratories report HIV diagnosis. In France, the proportion of under-reporting is higher, but 5,000 laboratories report HIV diagnosis.

Nineteen of 44 countries (43%) had not evaluated the timeliness of either their HIV or AIDS surveillance systems (i.e. time from diagnosis to report). Of the 18 countries that had done so, three had assessed timeliness of HIV reports only, two of AIDS reports only and 13 of both surveillance systems.

Of the 16 countries which reported the timeliness of their HIV reporting systems, all but three stated that 90% or more of HIV reports were received within six months (in Belarus, the UK and France, over 75% were received within six months). In contrast, of the 15 countries which reported the timeliness of their AIDS reporting systems, only eight stated that 90% or more of AIDS reports were received within six months, and six countries stated that 10% or more of AIDS reports were received with a delay of more than 12 months.

The validity of the HIV reporting system (e.g. comparison of the information provided on the original case report and the medical record) has been assessed in seven countries (100% in Andorra, Croatia and Czech Republic, 98% in Belarus). The validity of AIDS reporting system has also been assessed in seven countries (100% in Andorra, Croatia, Czech Republic and Republic of Moldova).

The completeness of HIV and AIDS reporting (i.e. percentage of cases with complete records on all variables) has been determined in 11 countries and varied from 23% to 100% for HIV cases and from 40% to 100% for AIDS cases. Separate percentages of completeness for the individual variables were not available.

Discussion

In 2006, HIV and AIDS case reporting systems were in place in almost all the 53 countries in the WHO European Region. Overall, data collection is computerised and case-based in most of the countries. National coverage for HIV case reporting has not yet been achieved in two countries (Italy and Spain). In Austria, HIV case reporting was based on a national cohort of HIV-positive patients. In comparison with a previous survey on HIV reporting in Western Europe, conducted in 1999 [8], HIV case reporting systems have since been implemented in two additional countries (France and Ireland) and in the Netherlands the reporting system has become a national one. HIV reporting in Europe is based on newly diagnosed cases, except at the start of a new HIV case reporting system (a few years need to pass before the system has stabilised and data can be interpreted). Another exception is imported cases, which have been previously diagnosed in the country of origin.

AIDS surveillance data no longer reflects the underlying trends in current HIV infection satisfactorily. However, it still provides some objective indication of the number of people in the advanced stages of HIV infection. According to a survey that was conducted in 2005 [9], AIDS case reporting was considered "somewhat useful but not as much as before" in almost half (17/43) of the countries in the WHO European Region. For example, AIDS case reporting is useful to assess the number of late HIV diagnoses [10].

FIGURE 3

Age cut-off for adolescent and adult AIDS case definition, WHO European Region, 2006

-  Countries using 1993 European AIDS surveillance case definition, but age cut-off is 15 years
-  Countries using 1993 European AIDS surveillance case definition, with age cut-off 13 years or other
-  Other definition
-  Unknown



Linkage between HIV and AIDS individual reports, which allows for better case follow-up, is possible in most European countries (either within the same database or by linkage of databases). In a few countries with a high case load it is still not possible, mainly because different HIV and AIDS case identifiers are used for reasons of confidentiality. Linking HIV and AIDS databases could allow assessment of HIV disease progression and evaluation of modalities for HIV testing and care practices.

Fear of breach of confidentiality remains an important issue for HIV reporting. Although most of the European countries used a coded identifier to detect duplicate reports, the patient's full name is still used in 11 countries. While the use of full names needs strict and enforceable regimes of confidentiality to secure the registries, the use of unique coded identifiers depends on the reliability of the encoding system to be replicated and to identify duplicate reports [11]. Among the nine countries that had been using full names to identify HIV cases in 1998 [12], five were still using names in 2005 (Czech Republic, Israel, Lithuania, Republic of Moldova and Russian Federation) and two countries (Poland and Serbia) were using a code based on the name in 2006 (information unavailable for the two remaining countries). In contrast, HIV surveillance in the United States was name-based in 2006 in almost all the states, but not at federal level [13].

Although most countries used the 1993 European AIDS Surveillance Case Definition, some criteria need to be standardised across the European countries (e.g. the age cut-off for adults and adolescents, which was 13 years in some countries and 15 years in others). The AIDS case definition has been recently revised by the European Centre for Disease Prevention and Control (ECDC) and the age cut-off for adults has been defined as 15 years. This new case definition will be published in the near future. In parallel, in order to better monitor HIV treatment needs, the case definition for HIV surveillance has been recently revised by the WHO to include a clinical and immunological classification of HIV-related disease [3].

Of the variables included in HIV and AIDS reports at the European level, some are currently collected by more than 90% of the countries (e.g. sex, age, dates of diagnosis and report of HIV and AIDS, transmission categories) and others are not systematically collected by all the countries (e.g. ethnicity, date of death, ART at AIDS diagnosis or CD4 count at HIV diagnosis). Standardisation of variables is needed at European level, not only to understand better the epidemic but also to ensure that the countries have a minimum of data available to help design or improve interventions (e.g. HIV testing policies, monitoring of ART). Collecting information on CD4 count as well as clinical stage at HIV diagnosis is useful to monitor the proportion of cases diagnosed with advanced HIV infection, information that can be used to target efforts aimed at reducing late diagnosis. CD4 counts will be collected at European level for the first time in 2007. Several countries also monitor the molecular biology of HIV. This information is used to identify HIV strains that share the same genetic pattern, improving the characterisation of risk factors of genetic and environmental origin. This approach can also serve to understand better resistance to HIV treatment.

Information on HIV resistance was collected in only a quarter of the European countries. However, surveillance of HIV resistance is often not reported systematically; it can be based on cohort studies or networks of laboratories participating on a voluntary basis. Monitoring HIV drug resistance is useful for public health

interventions or treatment monitoring [14]. While some guidelines recommend that HIV drug resistance surveillance should focus on individuals newly diagnosed with HIV in order to track transmitted resistance over time [14], other projects support genotypic resistance testing for all individuals who have not received antiretroviral drugs (recently and chronically infected) [15]. Different definitions are used to monitor HIV drug resistance, and the need to reach a consensus on the definition of drug resistance, especially for surveillance purposes, has been underlined [16].

In two-thirds of the countries, HIV and/or AIDS surveillance systems have been evaluated using one of four criteria: under-reporting, validity, completeness, timeliness. In countries where specific evaluations have been conducted, the percentage of under-reporting was higher and reporting delays longer for reporting of AIDS cases than of HIV diagnoses. In a survey conducted in 1996 [17], 32 European countries (71%) were able to provide quantitative estimates of under-reporting for AIDS cases. These estimates ranged from 0 to 25%. Completeness of HIV and AIDS reporting varied widely from one country to another (completeness of AIDS reporting has decreased in several countries, probably because clinicians no longer consider it equally important as before), and few countries have evaluated the validity of their reporting systems.

Although these four evaluation criteria were the ones most commonly used to evaluate HIV/AIDS surveillance systems, other assessment indicators (simplicity, flexibility, acceptability and representativeness) should also be used [18-20].

Conclusion and recommendations

HIV/AIDS case reporting data are crucial to support and guide public health policies for prevention and control of the HIV epidemic in the EU and the WHO European Region. Standardisation of HIV/AIDS surveillance system needs to be improved at European level in order to allow better comparability of data. The implementation of the revised European case definition for HIV/AIDS is the first step toward harmonisation and standardisation.

To achieve this goal, countries are advised by ECDC to have a surveillance system that collects individual data at a national level. Such a system should also ensure data confidentiality and respect the patients' human rights. Ideally, this surveillance system should integrate information on the three key stages of disease progression from asymptomatic HIV infection to death. For HIV diagnosis, the CD4 count at diagnosis provides valuable information for cases that present at a late stage of infection. For AIDS, information on treatment (HAART) is important to monitor access to care. For HIV/AIDS mortality, all causes of death, related to HIV or not, should be documented. Where possible, linkage between HIV/AIDS reporting systems and the mortality database is an added value. If this is not possible, other methods (e.g. surveys) can be conducted among HIV-infected persons. In addition, standard coding systems are needed to improve HIV/AIDS mortality surveillance [21].

Countries are further advised by ECDC to ensure that monitoring of HIV drug resistance is included in their current HIV surveillance system. WHO guidelines on this are available and these guidelines should be applied in the European Region [14].

The HIV epidemic is complex and its surveillance requires a multi-faceted approach, such as the development of "second generation" HIV surveillance which includes biological and behavioural data. This, as well as monitoring of HIV prevalence data, should be continued in addition to HIV case reporting.

Finally, it is advisable that the EU Member States evaluate their surveillance systems at appropriate and regular intervals as part of the data quality assurance process. A protocol for evaluation of surveillance systems would be a useful tool to strengthen HIV/AIDS surveillance in the WHO European Region.

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