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### **HIV Surveillance**

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#### 1. Introduction

Epidemiological surveillance is defined as the ongoing systematic collection, recording, analysis, interpretation and dissemination of data reflecting the current health status of a community or population. It is essential to planning, implementation and evaluation of public health practice and is closely integrated with the timely dissemination of these data to those who need to know. The definition emphasizes the use of data for public health action, not simply the collection of information as an end in itself.

The objectives of HIV surveillance include the provision of timely and reliable information for:

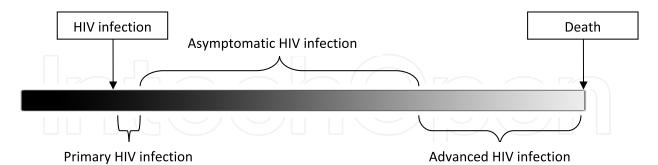
- advocacy for resources for prevention and care, mobilization of political commitment
- appropriate resource allocation between affected populations and areas
- effective targeting of prevention, care and support programmes
- monitoring and evaluation of the aggregate impact of programmes
- developing new programmes
- informing the public
- tracking the leading edge of the epidemic
- projecting future care and prevention needs
- identifying information gaps and guiding research to fill those gaps
- making health policies to maximize the effectiveness of the above.

So, HIV surveillance is trying to provide qualified evidences for decision makers to better response to HIV epidemic. In order to reach the above objectives, different elements of HIV surveillance has been developed and implemented in different settings. In this chapter we review these elements. Before addressing the different elements of HIV surveillance, we should have a view of HIV infection and its natural phases of infection.

#### 2. The natural history of HIV disease and disease stages

HIV infection results in a chronic condition which is started from *primary HIV infection* with unspecified signs/symptoms (such as fever, muscle aches and swollen glands). Then most affected persons have mild or no symptoms for several years. Gradually, as their immune

system weakens, they will experiences HIV-related clinical symptoms and illnesses. Without specific treatment, the HIV infected person will experience all clinical stages ended with the end-stage disease called AIDS (**Figure 1**).



#### Fig. 1. Key HIV stages which could be reported in HIV case reporting surveillance

HIV transmitted from an infected person to another mainly through:

- Unsafe sexual contact
- Unsafe drug injection
- Delivery of Breast feeding of a child by the affected mother
- Unsafe blood transfusion

As it's obvious, there drivers of the HIV epidemics in a community are risk behaviors. To control the spread of the HIV epidemic, we need to collect information not only on the number of affected people and their previous risky behaviors, but also gather strategic information on the behaviors of the subpopulations especially who are most at risk for acquiring the HIV infection naming female sex workers, injecting drug users, men who have sex with men. Second generation surveillance for HIV/AIDS has been proposed by WHO and UNAIDS to provide such information to response to HIV/AIDS epidemic efficiently.

Second generation surveillance for HIV/AIDS is the regular, systematic collection, analysis and interpretation of information for use in tracking and describing changes in the HIV/AIDS epidemic over time. Second generation surveillance for HIV/AIDS also gathers information on risk behaviors, using them to warn of or explain changes in levels of infection. As such, second generation surveillance includes, in addition to HIV surveillance and AIDS case reporting, STI surveillance to monitor the spread of STI in populations at risk of HIV and behavioral surveillance to monitor trends in risk behaviors over time. These different components achieve greater or lesser significance depending of the surveillance needs of a country, determined by the level of the epidemic it is facing: low level, concentrated or generalized.

The core elements of HIV/AIDS Surveillance included

- HIV/AID Case Reporting
- It's comparable as disease routine reporting system. Persons diagnosed HIV infection (clinical stages 1-4) and/or advanced HIV disease (clinical stages 3 and 4) registered and reported systematically through the health system.
- HIV sentinel sero-prevalence Surveys
- In some health centers, blood is collected routinely for other proposes such as routine antenatal cares for pregnant women. A portion of this blood can be used for HIV testing.Behavioral Sero-Surveys (or Bio-Behavioral Surveys)
- Surveys of HIV-related behavior that involve asking a sample of people about their risk behaviors, such as their sexual and drug-injecting behavior. In addition to behavioral questionnaire, blood or saliva also collected to be tested for HIV and/or other sexual

#### **HIV Surveillance**

transmitted diseases. In some settings test for tuberculosis is also integrated. Data on behavioral and serological exams are linked and analysis jointly to provide more comprehensive information on the HIV epidemics and its determinants. These Bio-Behavioral surveys could be divided into two categories: (1) facility based surveys (2) community bases surveys. The main differences between these two methods are coming from the sampling schemes that applied for recruiting the subjects into the survey and the definition of the target population.

We elaborate different components of HIV surveillance by the course of HIV infection in Figure 2. Surveillance for HIV infection could be done at four key points: Before, at, after the time of HIV infection and death:

- Surveillance components at the phase before acquiring HIV infection (Behavioural and STI):

It includes Behavioural and STI surveillance activities. Surveys for estimating the prevalence of risky behaviours and inadequate knowledge on ways to prevent HIV transmission are measures among the general population or high-risk subpopulation (i.e FSWs, IDUs and MSM depend on the context). Sexual Transmitted Infections (STIs) surveillance is also helping the country to track the high-risk populations who are susceptible to get the HIV infection through sexual routes. STIs treatment and care will reduce this susceptibility.

- Surveillance components at the time of acquiring HIV infection (Incidence):
- It's addressing the surveillance activities which could provide an estimated of HIV incidence. HIV incidence is very hard to be estimated and new methods are proposed and implemented. However, many countries did not apply these methods as they are expensive and also laboratories do not have the capacities to do these new tests. As a strategic alternative, it's recommended to include early infant diagnosis surveillance for having a proxy for incidence measures.
- Surveillance components after acquiring the HIV infection (Morbidity): These include a verity of surveillance activities such as HIV case reporting, Advanced HIV case reporting, prevalence studies among the general population or high-risk groups, sentinel HIV surveillance among specific groups such as pregnant women at the antenatal clinics. These activities will provide information on the direction of the
- HIV epidemic in the population and the burden of disease. HIV drug resistance studies also included as the advance component of this phase
- Surveillance components of dead AIDS cases (Mortality):

This part includes vital registry of all cases died due to AIDS. The rest of the chapter focuses on HIV case reporting surveillance. If you are interested on

the other components such as Sentinel HIV Surveillance and Bio-Behavioral Surveys, more could be found in Guidelines for conducting HIV sentinel serosurveys among pregnant women and other groups (2003) and Guidelines for repeated behavioral surveys in populations at risk of HIV; Durham, North Carolina, Family Health International (2000).

#### 3. HIV case reporting

As one part of the HIV surveillance system, HIV in all clinical stages (including advanced HIV cases and AIDS) is an ongoing reporting system in many countries including the lowand middle-income countries. Since 2006, World Health Organization (WHO) has recommended to replace AIDS case reporting with HIV cases and advanced HIV infection.

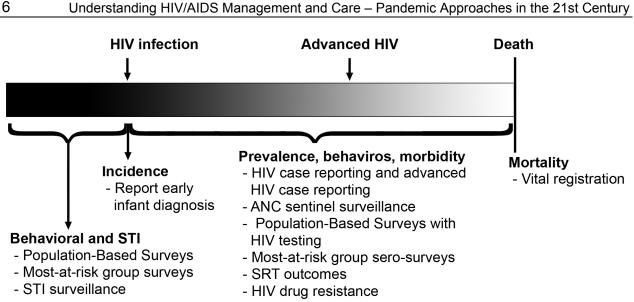


Fig. 2. Key HIV Surveillance Component by phases of HIV infection [Advances and future directions in HIV surveillance Diaz et al. Curr Opin HIV AIDS 4:253-259]

These identified cases are reported confidentially either by names or by anonymous codes. HIV case reporting refers to the methods used to capture individual-level information about persons with HIV infection. Each person with HIV infection is reported using a single case report form which contains information pertaining only to that person. This type of reporting occurs at the level of the health facility and is forwarded to the local level as individual case reports. The local-level surveillance officers combine the data and forward them on to the national surveillance programme where they will be computerized.

WHO refers to reporting all stages of HIV as "HIV infection reporting (all clinical stages)" (Table1) and to reporting of advanced HIV (clinical stages 3 and 4 only) as "advanced HIV infection (disease) reporting." Reporting advanced HIV infection includes AIDS.

Adults and children 18 months or older	HIV infection is diagnosed based on: Positive HIV antibody testing (rapid or laboratory-based enzyme immunoassay). This is confirmed by a second HIV antibody test (rapid or laboratory-based enzyme immunoassay) relying on different antigens or of different operating characteristics; and/or; Positive biological test for HIV or its components (HIV-RNA or HIV- DNA or ultrasensitive HIV p24 antigen) confirmed by a second virological test obtained from a separate determination.
Children younger than 18 months:	HIV infection is diagnosed based on: positive virological test for HIV or its components (HIV-RNA or HIV- DNA or ultrasensitive HIV p24 antigen) confirmed by a second virological test obtained from a separate determination taken more than four weeks after birth. Positive HIV antibody testing is not recommended for definitive or confirmatory diagnosis of HIV infection in children until 18 months of age.

Table 1	. WHO	case	definition	for	HIV	infection
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Cases diagnosed with advanced HIV infection (including AIDS) not previously reported should be reported according to a standard case definition. Advanced HIV infection (Table 2) is diagnosed based on clinical and/or immunological (CD4) criteria (Table 3) among people with confirmed HIV infection. AIDS case reporting for surveillance is no longer required if HIV infection or advanced HIV infection is reported.

Advanced HIV infection is diagnosed based on clinical and/or immunological (CD4) criteria among people with confirmed HIV infection:

Criteria for diagnosis of advanced HIV (including AIDS) for reporting

**Clinical criteria** for diagnosis of advanced HIV in adults and children with confirmed HIV infection:

• Presumptive or definitive diagnosis of any stage 3 or stage 4 condition.

and/or;

**Immunological criteria** for diagnosing advanced HIV in adults and children five years or older with confirmed HIV infection:

• CD4 count less than 350 per mm3 of blood in an HIV-infected adult or child.

and/or;

**Immunological criteria** for diagnosing advanced HIV in a child younger than five years of age with confirmed HIV infection:

- %CD4+ <30 among those younger than 12 months;
- %CD4+ <25 among those aged 12–35 months;
- %CD4+ <20 among those aged 36–59 months.

Table 2. WHO case definition of advanced HIV (infection or disease) (including AIDS) for reporting<sup>1</sup>

	Age-related CD4 values				
HIV-associated immunodeficiency	<11 months (%CD4+)	12–35 months (%CD4+)	36 –59 months (%CD4+)	>5 years (absolute number per mm3 or %CD4+)	
None or not significant	>35	>30	>25	> 500	
Mild	30–35	25-30	20–25	350-499	
Advanced	25–29	20-24	15-19	200-349	
Severe	<25	<20	<15	<200 or <15%	

Table 3. WHO immunological classification for established HIV infection

<sup>1</sup>World Health Organization, WHO case definitions of HIV for surveillance and revised clinical staging and immunological classification of HIV-related disease in adults and children. 2007

#### 4. Events which could be reported in HIV case reporting

HIV case reporting, if developed / implemented properly, can provide the health authorities necessary information which are needed for better understanding of the HIV epidemic and monitoring the success of the programmes. The reported cases at any stages of the disease could be used for producing the following indicators:

- HIV incidence (the number or percentage of new HIV infections)
- HIV prevalence (the number or percentage of all persons living with HIV, regardless of how long they have been infected or whether or not they are aware of their infection)
- The incidence of advanced HIV infection
- The prevalence of advanced HIV infection
- Deaths from advanced HIV infection.

#### 5. Elements of a case report form

A comprehensive case report form should include:

- Administrative information
  - Name and address of facility where the report is submitted from (reporting source)
  - Date form completed
  - Report status (new or update)
- Demographic information
  - Patient identifier (name or code)
  - Date of birth
  - Sex

8

- Current status (alive, dead, unknown)
- Country of residence
- Information on the patient's HIV-related risk behaviour
  - Sex with male
  - Sex with female
  - Injected non-prescription drugs
  - Perinatal/MTCT
  - Blood transmission-related variables
- Occupational exposure
- Diagnosis information
  - Date of HIV diagnosis
  - Facility of diagnosis
- HIV clinical stage
  - Date of first clinical stage
  - Clinical stage
  - Date of first clinical stage 3 diagnosis
  - Date of first clinical stage 4 diagnosis
- Immunologic status
  - Date of first CD4 test
  - Result of first CD4 test (count and/or percentage)
  - Date of first CD4 count <350 cells/mm<sup>3</sup>
  - Date of first CD4 count <200 cells/mm<sup>3</sup>

- Care and treatment
  - Use of ART
    - Date first used ART
  - Use of prophylaxis against Pneumocystis jirovecii pneumonia
- Vital status
  - Date of death
  - Cause of death.

Countries should carefully consider which elements to include in the case report form. It should include only information that is readily available to the person completing the form and that can be collected from most of the reporting facilities. It should not be a burden to people who complete it.

#### 6. Flow of data

We elaborate this section by presenting an example of health system in a country which medical universities providing health for the people in all areas of the country. Here, the flow of data is divided into four levels (**Figure 3**).

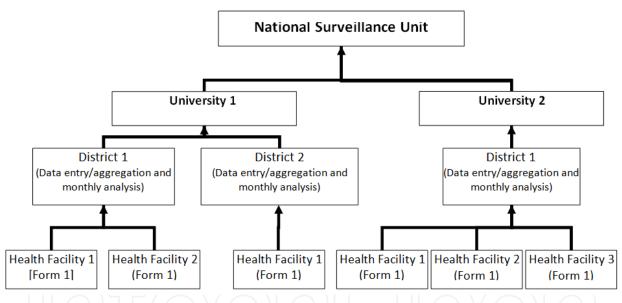


Fig. 3. Flow of data in a country designed in four levels

**Level 1 - Health Facilities**: all urban and rural health centers, clinics, hospitals, private offices at the time of diagnosis an HIV case in all clinical stages should report the case.

• Activities: the responsible staff fill Form 1 for every one who meets the case definition and report the case to level 2

**Level 2 - District health centers**: these are district health centers which are responsible for providing health to district inhabitants.

• Activities: every month, the responsible staff will compile the received data and then fill an aggregated data reporting form and submit it to the Center for Disease Control of the University. By doing sort of data analysis, feedbacks developed and send to the health facilities working in the district.

Level 3 - Center for Disease Control at the University:

• Activities: every month, the responsible staff will compile the received data and then fill out an aggregated data reporting form to be sent to the Center for Disease Control of the Ministry (National Surveillance Unit). By doing sort of data analysis, feedbacks developed and send to the district health centers.

Level 4 - Center for District Control at the Ministry (National Surveillance Unit):

• Activities: every three months, the responsible staff will compile the received data, make a comprehensive analysis on the received data, and draft the quarterly national surveillance report and distribute it to all the stakeholders to be used.

#### 7. Analysis and feedbacks on cases reporting surveillance

Most of the time, analysis of surveillance data is mainly done only by descriptive analysis to estimate the level of indicators such as the number of affected people by sex, percentage of those cases reported sexual contact as the most probable route of transmission. These estimates should be interpreted according to time to explore the trends and direction of the epidemic. As an example, here we elaborate the analysis and feedback steps of a national HIV case reporting surveillance (in line with the previous section)

**Level 2 feedbacks**: every three months, HIV surveillance report including the last status of HIV in the district and the trend analysis of the reported data should be sent to all health facilities (even if they did not reported any case of HIV during the period). Such report should have at least the following information:

1. Three months trend

10

- 2. Three months trend in compare to the previous three-month period
- 3. Total number of reported cases by age and sex groups including the main routes of transmission.

**Level 3 feedbacks**: every three months, HIV surveillance report including the last status of HIV in the province and the trend analysis of the reported data should be sent to all district health centers (even if they did not reported any case of HIV during the period).

Such reports should have at least the following information:

- 1. Three months trend
- 2. Three months trend in compare to the previous three-month period
- 3. Total number of reported cases by age and sex groups including the main routes of transmission.

**Level 4 feedbacks**: every three months, HIV surveillance report including the last status of HIV in the province and the trend analysis of the reported data should be sent to all district health centers (even if they did not reported any case of HIV during the period).

Such reports should have at least the following information:

- 1. Three months trend
- 2. Three months trend in compare to the previous three-month period
- 3. Total number of reported cases by age and sex groups including the main routes of transmission.

If an increase of 10% has been observed in a university for a period of two sequential months, the feedback should be send to that university and the neighborhood universities at the earliest convenience. It should be done separately from the CDC three-month report.

#### 8. Core indicators according to the phases of the infection

- Surveillance components at the phase before acquiring HIV infection (Behavioural and STI):

As mentioned before, here the focus is on measuring the risky behaviors which make people susceptible for acquiring the infection. So, samples of people requited in a behavioral survey and complete a questionnaire including sections for sexual behaviors, drug injection and knowledge for HIV prevention, and history of HIV testing and counseling. This data is applied for produce behavioral indicators which used to compare populations, geographic areas and programme impact over time. Examples of these interfamily wide-use indicators are:

- percentage of women and men aged 15–49 who received HIV testing in the previous 12 months and who know their results
- percentage of most-at-risk populations reached by HIV prevention programmes
- percentage of young women and men who have had sexual intercourse before the age of 15
- percentage of female and male sex workers reporting use of a condom with their most recent client
- percentage of injection drug users who reported using sterile injection equipment the most recent time they injected
- Surveillance components after acquiring the HIV infection (Morbidity):
- Percentage of young women and men aged 15 to 24 who are HIV-infected
- Percentage of most-at-risk populations who are HIV-infected.

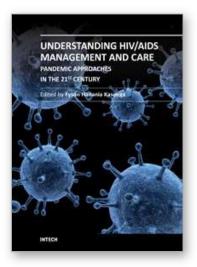
Although different indicators have been proposed by many international bodies including UNAIDS and WHO, countries should decide from which they will benefit from and is much related to the context and their level of HIV epidemics. They should define the target groups of HIV surveillance and adopt the indicators accordingly.

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Understanding HIV/AIDS Management and Care - Pandemic Approaches in the 21st Century Edited by Dr. Fyson Kasenga

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Like any other book on the subject of HIV/AIDS, this book is not a substitute or exhausting the subject in question. It aims at complementing what is already in circulation and adds value to clarification of certain concepts to create more room for reasoning and being part of the solution to this global pandemic. It is further expected to complement a wide range of studies done on this subject, and provide a platform for the more updated information on this subject. It is the hope of the authors that the book will provide the readers with more knowledge and skills to do more to reduce HIV transmission and improve the quality of life of those that are infected or affected by HIV/AIDS.

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