HEALTH PROMOTION AND DISEASE PREVENTION A Handbook for Teachers, Researchers and Health Professionals and Decision Makers	
Title	General Objectives and Methods in HIV/AIDS Surveillance
Module: 5.4	ECTS: 0.5
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Key words	AIDS, HIV, surveillance, assessment, risk, method, indicator
Learning objectives	<ul> <li>After completing this module students and public health professionals should (for example):</li> <li>Be aware of the importance of HIV/AIDS surveillance;</li> <li>Recognise the menace of epidemics;</li> <li>Increasing knowledge of all levels of professional and trainees;</li> <li>Identifying the weak points and improving them;</li> <li>Improving the steps in organizing behaviour surveillance studies;</li> <li>Improving the quality of care in HIV/AIDS field.</li> </ul>

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Abstract	Preventing transmission of virus is still the single intervention known as effective in limiting the spread of HIV infection. So, the epidemiological surveillance of HIV/AIDS is an important tool used by public health specialists in controlling epidemics. Epidemiological surveillance is a continuous process of collecting, analysing, interpreting and disseminating data in order to plan, implement and assess public health interventions. The objectives of HIV/AIDS surveillance should be specific, measurable, transformed into actions, realistic, planned to be done in due time. The main methods used by HIV/AIDS surveillance in collecting the data are biological surveillance, behavioural surveillance, other sources of information. The main indicators recommended for any HIV/AIDS programme components include the fields of politics, condoms availability and quality, social stigmatus & discrimination, knowledge, vertical transmission, sex negotiation and attitude, sexual behaviour, especially in youngsters, injection with drugs, safe blood and derivatives, STI treatment and prevention, care and social support, social & health impact. Data collected by public health surveillance systems guide the responses to the events, measure and monitor the burden of the disease, assess public health politics, etc Integrated approach in epidemiological surveillance takes into account, generally, the integration of all activities that have to do with epidemiological surveillance into a single service with multiple functions using the same structures, procedures and personnel. Second generation HIV/AIDS surveillance is a WHO concept developped on modular systems. The metodology in risk behaviour surveillance studies includes: justifying, behavioural risk, methods for collecting data, behavioural data value, steps in organizing behavioural surveillance studies.
Teaching methods	Teaching methods could include lectures, exercises, individual work, interactive methods such as small group discussions, seminars etc. The teaching process should be organised in courses including interactive sessions of questions and answers, epidemiology, clinical, and laboratory practice.
Specific recommendations for teachers	Work under teacher supervision (abovementioned) 70% / Individual students' work 30%. Powerpoint presentations, experts in practical issues, access in epidemiology, hospital and laboratory facilities, course and practice books, target audience composed by students and trainees.
Assessment of students	<ul> <li>Assessment could be based on:</li> <li>1. multiple choice questionnaire (MCQ),</li> <li>2. structured essay,</li> <li>3. interview,</li> <li>4. case problem presentations.</li> </ul>

# GENERAL OBJECTIVES AND METHODS IN HIV/AIDS SURVEILLANCE Adrian Tase, Luminita Titu

The aquired immunodeficiency syndrome (AIDS) epidemic is one of the greatest challenges facing the medical community today. Infection with human immunodeficiency virus (HIV) (1) is a dynamic process characterized by intense viral replication, CD4 lymphocyte depletion, and profound immunodeficiency (2).

HIV/AIDS infection is fatal. In 2004 there were recorded 3.1 million deaths because of AIDS all over the world. Among them, 500.000 cases were children under 15 years old.

Since the first reports of AIDS published in 1981, the vast majority of cases worldwide has been caused by HIV-1(3,4)Another retrovirus, HIV-2, is a prevalent cause of AIDS in Western Africa (5)

Improved understanding of HIV pathogenesis has led to rational drug development, sound treatment principles, and decreased morbidity and mortality due to AIDS (6,7). There is an interesting risk model, that simulates coronary heart disease, in order to predict some therapeutic effects (8)

Surveillance and therapeutic strategies evolve rapidly, and errors may have dire and irreversible consequences. It is therefore recommended that HIV infection be managed only by practitioners with specific and expertise in surveying and treating the disease.

#### **Reasons in Supporting HIV/AIDS Surveillance**

The antiretroviral therapy developped a lot in the recent years, but there hasn't been found yet an effective treatment against AIDS infection. However, efforts have been made in order to discover an efficient way of immunisation for the individuals against the risk of catching the infection. Though in advanced phase, no vaccine aquired yet the licence for use in medical practice.

The single intervention known as effective in limiting the spread of HIV infection is preventing the virus to be transmitted.

HIV infection and AIDS disease develop a pandemic evolution. The magnitude of the pandemics is growing incrementally in some geographical areas - South Saharian Africa, South-East Asia and Eastern Europe , (9, 10, 11).

The magnitude of the AIDS epidemics impacts the medical services, social and family life, demography and economy of each country burdening both individuals and society.

HIV/AIDS pandemics consists in many epidemics with various dynamics. Moreover, across different countries, the dynamic of the epidemics changes during the evolution, modifying the natural history of the disease.

Regarding this continuous threat, the humankind should involve a bigger amount of resources and should adapt the answer at all times. The global expenses for HIV/AIDS reached 8.3 billion USD in 2004, about 12 billion USD in 2005 and about 15 billion USD in 2006.

Epidemiological surveillance of HIV/AIDS is one of the most important tools used by public health specialists in controlling HIV/AIDS epidemics.

Epidemiological surveillance is a continuous process of collecting, analysing, interpreting and disseminating data in order to plan, implement and assess public health interventions.

The main principle of the epidemiological surveillance is "info for action" -i.e. gathering the necessary information and using this to control the disease.

The basic features of epidemiological surveillance are (12):

- spotting the events;
- recording the events;
- confirming the diagnosis;
- reporting the events;
- analysing the reported data;
- disseminating the results.

The HIV/AIDS surveillance data allow monitoring the evolution of epidemics and the understanding of changes that might appear during the dynamic or the natural history of the disease.

The HIV/AIDS surveillance data are useful in:

- knowledge of the infection spreading among population, and
- estimate the burden of the disease.

In the specific case of HIV infection, the behavioural description of vulnerable people for catching the infection allows anticipating the ways of spreading the disease (13).

This information is used by the specialists in identifying and planning the intervention as well as by the political stakeholders and fundsraisers in decision making concerning the medical and social resources.

The surveillance data are also used to assess the success of the interventions which limit the disease spreading.

# Main Goals and Types of Surveillance in HIV/AIDS field

The objectives of HIV/AIDS surveillance should meet the following criteria (SMART):

- Specific to serve the purposes of the surveillance, i.e. to understand and to explain the evolution of HIV/AIDS epidemics and to identify, plan, implement and assess interventions;
- Measurable for each objective there might be defined a set of indexes which monitor the changes;
- transformed into Actions for each objective there might be identified specific actions (knowledge, intervention, behaviour, morbidity);
- Realistic i.e. they might be done using the resources provided;
- planned to be done in due Time the changes aimed by the objectives should be projected during a certain period, taking into consideration all the data and knowledge at the moment of elaboration (14).

To establish the goals of a surveillance programme (see table 1), we must take into account the phase of the epidemics, the need of explaining the evolution or/and the natural history of the disease, the available resources as well as the objectives of the intervention schedule to reduce HIV infection. Each type of surveillance is due to a certain phase in the natural history of the disease, as it is shown in chart 1. (to be inserted)

Objectives	Types
HIV cases estimation at national/local level	Surveillance of the women who address to prenatal clinics (sentinel) Serological studies (HIV tests) among population in general Serological studies among special groups of population - high risk of HIV infection
Describing the behaviour in case of risk	<ul> <li>Behaviour studies (quality / quantity)</li> <li>general population</li> <li>special groups of population with high risk of HIV infection classifying the cases of HIV / AIDS in groups of risk behaviour</li> </ul>
AIDS morbidity assessment	<ul> <li>AIDS surveillance</li> <li>universal AIDS reporting (passive / active)</li> <li>sentinel AIDS reporting (passive / active)</li> <li>using the data from the antiretroviral therapy (16) programmes Surveillance of Accidental Infections</li> <li>Accidental Infections reporting</li> </ul>
AIDS mortality assessment	Revising the data from the death records

#### Table 1 - Objectives of HIV/AIDS surveillance and types of surveillance

Source: World Health Organisation Guide (15)

## Methods of gathering the data used in HIV/AIDS Surveillance

The methods used by HIV/AIDS surveillance in collecting the data could be classified in three cathegories:

- Methods for biological surveillance
- Methods for behavioural surveillance
- Using other sources of information

## **Biological** surveillance

Biological surveillance uses the following methods: serological surveillance sentinel type, regulary screening, transversal and repeated serological studies.

Serological surveillance sentinel type

Serological surveillance sentinel type means watching over the HIV infection cases among target groups population - *sentinel population* and institutions that they address to - *sentinel institutions*.

Examples of sentinel populations:

- Women that need prenatal control;
- Sexual Transmission Infections patients;
- Drug users;
- Prostitutes;
- Homosexuals, with some particular points of race / ethnicity (17).
- Examples of sentinel institutions:
- Prenatal consulting clinics;
- Dermato-Venerological clinics;
- Rehabilitation clinics.

Obviously, the serologic tests are mandatory. When blood is collected in other purpose, it must be used *anonymous* HIV tests for the rest of the serum, after erasing all personal data. This can work together with before and after testing advising. When these samples enter the system without personal data, they are called *voluntary anonymous testing*.

Interpretation of the results must take into account if the population in the sentinel institutions is representative.

Regulary screening:

- of donated blood = cheap and useful to estimate the infection level among general population, and
- of occupational groups = young men recruits have a good representativity; employees from certain industries may differ considerably from the general population *healthy employee effect*

Transversal and repeated(18) serological studies

- in high risk population groups with unidentified sentinel groups;
- in general population large studies.

These include Ac anti-HIV testing of individuals from selected groups, at a certain period, from target population, following certain rules. The consent of the person selected to be tested is mandatory. The are complicated and expensive. The access to the group population of high risk is difficult, that's why the scientific accuracy of the methods and, respectively, of the results, is limited.

#### Behavioural surveillance

Qualitative behavioural studies

This type of studies are led with small group of persons, using direct methods (experimental, observational), or indirect methods (focus groups, experts analysis, case studies). They allow a deep approach of the problem in order to get the meaning, but cannot assess the changing behaviour during the time.

Quantitative transversal repeated behavioural studies

This type of studies is conducted in:

- general population;
- populational groups with high risk of HIV transmission.

They include transversal behavioural studies in representative groups of target population at high risk at a certain time. They follow the same methodology when repeating for comparing the results. For a good representativity, the randomisation is highly recommended.

Behavioural studies provide informations about the level and the distribution of behavioural-related risk among the population, the surveillance of these evolving features, as well as the assessment of success in some interventions, if they aim changing behaviour in risky cases.

Connecting behavioural and biological data helps understanding the dynamic of HIV/ AIDS epidemics. Connecting behavioural studies with HIV testing for the same individuals is not recommended, because they are likely to refuse participation.

#### Using other sources of information

This includes: new HIV/AIDS reported cases, death records, surveillance of STI and tubercolosis, data from therapy programmes.

#### New HIV/AIDS reported cases

There are two types of AIDS reporting:

- universal (complete), and
- sentinel type.
- Each of them can be:
- passively led (cases are introduced into the system as they are reported by the clinics), or
- actively led (cases are introduced into the system through a periodical checking of clinic records made by specific personnel).

The features of the system depend on case definition and correlation with diagnosis resources.

A common problem of the systems based on reporting is the delay. Moreover, the passively led systems underestimate the cases.

AIDS reporting has a peculiar importance in pediatric HIV/AIDS surveillance, because the serological diagnosis has no relevance under the age of 18. That's why this should be strengthen. There are some countries that have already introduced the HIV-positive reporting system.

#### Death records

There are countries where the monitoring system of the vital data gathered from death certificates provide information on AIDS dying cases (19). Checking the distribution of death cases on age groups and causes can indicate an increase of the number of deads at young ages without catastrophic causes or can indicate an increase of this number because of tuberculosis or non-Hodgkinian limphoms, both suggesting an overmortality that might be caused by AIDS. The mortality data could underestimate AIDS as a death cause, because incomplete reporting.

Surveillance of Sexual Transmission Infections (STI) and Tuberculosis, other respiratory and non-respiratory diseases

STI is an important feature of a potential exposure to HIV both for having a role on HIV infection and for spotting unprotected sexual contacts with accidental partners.

STI shows a risky sexual behaviour in the recent past. The increase of STI cases can work as an alarm system against the risk of HIV spreading before the virus circulation among people.

That's why it is highly recommended STI to strongly survey STI and integrate this into HIV surveillance. Testing the patients with tuberculosis directly implies the treatment of pacients with double infection, but there was also noticed a connection between the increasing number of seropositive cases among tuberculosis patients and HIV cases in general population. Therefore these pacients might be sentinel population. When tuberculosis is associated in AIDS patients, there are years of HIV infections.

Concerning other respiratory infections, we can mention Pneumocystis pneumonia(20), or Pneumocystis jirovecii (21). We also mention fungal opportunistic infections in HIV disease(22).

Generally, children are more vulnerable to opportunistic infectious, even when treated with antiretroviral therapy(23).

We mention some non-respiratory comorbidities in HIV/AIDS patients: hypothyroidism<sup>1</sup>, Crohn's disease (25), depression (26), non-Hodgkin lymphoma (27), colorectal cancer (28).

Data from Therapy Programmes

Taking into account that, nowadays, there is an active antiretroviral therapy, we consider that AIDS surveillance should include persons access monitoring to this therapy (29), as well as the impact of antiretroviral agents on disease evolution.

# Surveillance Assessment & Major Indicators in HIV/AIDS Surveillance

Epidemiological surveillance is a scheduled activity that should be periodically assessed to guarantee quality, efficacy and usefulness. The assessment of the epidemiological surveillance systems includes a number of activities which purpose is to analyse the main features of a surveillance system.

The recommendations of CDC - Center for Disease Control and Prevention Atlanta for the assessment of a surveillance system, include the following tasks:

A. Responsible involvement into the assessment procedure;

- B. Description of surveillance system to be assessed:
  - the importance of the event under surveillance for public health;
  - the purpose, objectives and operating method;
  - the resources used in system operating.

C. Specific assessment schedule:

- the purpose of the assessment;
- the beneficiaries;
- the way of using the results;
- the items in the questionnaires;
- the standards for an effective assessment of the system.
- D. Documentation for the effective system:
  - availability actions generated by data analysis;
  - system features: simplicity, flexibility, quality of data, tolerability, sensitivity, positive predictable value, representativity, punctuality, stability;
- E. Conclusions & Recommendations definitions and supports;
- F. Pragmatism in using the results.

Epidemiological surveillance takes place within HIV/AIDS national programmes, as an instrument in monitoring and assessment of each public health programme.

The aquired knowledge on HIV spreading and the ten years experience, increased the interest of governments, funds donors and programme coordinators in monitoring and evaluation of HIV/AIDS programmes in order to provide documents for the success of these programmes and to use the resources more efficiently.

The final purposes of each HIV/AIDS programme are:

- reducing HIV spreading;
- improving care for infected persons;
- improving social & economical impact on communities.

<sup>1</sup> Bongiovanni M, Adorni F, Casana M, et al.. Subclinical hypothyroidism in HIV infected subjucts, J. Antimicrob. Chemother., 58:1086-1089, 2006.

To reach its investment purposes in the system (finances, human resources, time) a programme should generate interventions (surveillance data, informational support, services for the patients).

If the interventions are well thought and reach the target population, there can be expected positive effects on short term, like:

- condom using during the sexual intercourses with accidental partners;
- not using the same syringe for drug injection;
- first sexual intercourse at an older age;
- understanding the epidemics of the disease.

This short terms positive effects generate a long term positive impact reflected in:

- prevention strategies;
- decreasing the number of HIV infections;
- STI or decreasing the number of death cases because of HIV.

Monitoring consists in checking the prior information regarding a programme development and its results during the time. It also takes into account priority investments into the system and interventions generated by this one using records or reports, direct observation or studies among the benefit stakeholders. Monitoring could include short term positive effects and long term positive impact where information is generated by epidemiological surveillance systems.

Assessment is the procedure of regularly measuring the results, values and the impact on public health. This supposes connecting a result with an intervention.

Assessment could be done on three levels:

- process assessment (investments, activities, interventions);
- results assessment (if the activities were acomplished and interventions reached the target population, then we can take into account short term positive effects assessment, e.g. improving knowledge, behavioural changes, etc.);
- impact assessment (if the results assessment indicates knowledge progress, attitude and behaviour, then the assessment of positive impact on health status of the target population is justified).

Assessment belongs to public health programmes management and becomes objective through a periodical calculation of an indicators set and a comparison of pair indicators. For each level, there are clearly defined indicators that use data gathered by the administrative systems of the programme or the epidemiological surveillance systems.

Indicators used should be defined beginning with the stage of planning HIV/AIDS programmes to aquire a database necessary to compute it.

Indicators are:

- quantitative absolute numbers, rates, reports, proportions, and
- qualitative statements of the activities and results predicted in the objectives of a programme.

In an evaluational purpose of assessment in the field where an indicator was defined, this one should have the following features:

- relevant for programme objectives, measuring important aspects for HIV spreading and interventions;
- experience showing that the necessary information is available and may be collected;
- sensitive able to detect changes during the time, monitoring the aspect;
- available to measure what is expected to do for a correct interpretation;

- specific not measure any aspect that could generate bias in interpretation;
- reproductible using the same methods in different moments and places, standard indicators for comparison of results;

Indicators measure both investments and interventions in the programme: educated persons, condoms distribution, services provided, surveillance data.

These lead to short term effects: better knowledge, behaviour changing, protective sexual behaviour, epidemiological understanding of the disease, which, in turn, generate long term impact programme: prevention strategies, reduced number of HIV and STI cases. So, the objective of the assessment is reached.

Result indicators measure relevant aspects for HIV transmission that can be modified by interventions: knowledge, attitude, concepts, practice, medical or social services, provisions of necessary condoms or medicines, funds for HIV prevention, etc.. Once changed, they have a sure effect over HIV epidemics and AIDS pacients survival and life quality of HIV infected persons.

Taking into account the epidemiology of HIV infection the following aspects are relevant for HIV transmission and AIDS pacients survival:

- risk of sexual/blood contact with a HIV infected person influenced by: HIV cases in general population; number of sexual contactors per person and their features (age, prostitution, etc.); using the same syringe for drug injection; getting infected blood (transfusion screening);
- risk of virus transmission during the contact with a HIV infected person influenced by: condom use, STI presence, age and gender of non-infected person, type of sexual practice, stage of infection, etc.;
- how old is the infection influenced by: offer and access to therapeutical and care services for infected persons.

There is a set of indicators for any HIV/AIDS programme component - Table 2

Field	Indicators
Politics	1. effort index of the programme
	2. HIV prevention expenses
Condoms availability and	1. condoms availability at national level
quality	2. condoms availability when sold
	3. condoms quality
Social stigmatus	1. accepting HIV positive persons
& discrimination	2. non-discriminatory attitude personnel
Knowledge	1. general knowledge of HIV prevention methods
	2. no incorrect concepts on HIV
	3. how to prevent HIV transmission among homosexuals
	4. how to prevent HIV transmission among drug users
	5. vertical transmission prevention

#### Table 2. Indicators for HIV/AIDS programme fields

Advising and	1. persons who asked for testing and got answer
voluntary testing	2. county advising and testing
voluntary tosting	3. advising and testing quality
	4. advising centers with minimum conditions
	5. laboratory quality
Vertical transmission (31)	1. pregnant women advised and tested
	2. prenatal clinics for advising and testing
	3. HIV advising quality for pregnant women
	4. antiretroviral therapy
Sex negotiation	1. women ability to negotiate
and attitude	2. prostitution
Sexual behaviour	1. sex with high risk of HIV
	2. using condom at last sexual intercourse with high risk
	3. prostitution in the last year
	4. using condom by the customer at the last sexual intercourse
	with a prostitute
	5. using condom by a prostitute with the last customer
	6. homosexual sexual intercourse during the last year (32)
	7. using condom at the last sexual contact by the homosexuals
Youngster sexual	1. the age at the first sexual intercourse
behaviour	2. yougers having sexual relationships before marriage
	3. using condom at the last before marriage sexual intercourse
	4. youngers with multiple partners
	5. using condom during the last high risk sexual intercourse
	6. using condom during the first sexual contact
	7. sexual relationships among partners with various ages
Injection with drugs (33)	5. using the same equipment by the drug users
	6. not using the same equipment by the drug users
	7. injectable drug users who used condoms during the last sexual intercourse
Safe blood and	1. blood units screening
derivates	2. low number of blood transfusions
	3. blood banks at county level
	4. accidental transmission in sanitary units
STI treatment & prevention	1. STI diagnosis and treatment
	2. advising regarding STI
	3. STI care and medicine services
	4. STI treatment requirement
Care and social	1. AIDS trained medical personnel
Support	2. sanitary units for AIDS pacients
	3. sanitary units with medicines storage
	4. helping families with youngers care
	5. helping families with orphans care
Social & health (34) impact	1. HIV cases among pregnant women
	2. syphilis cases among pregnant women
	3. HIV cases in high risk population groups
	4. cases among orphans
	5. orphans education

Source: UNAIDS (30)

Technical details about the definition, the meaning of each indicator and the necessary instruments can be found in WHO/UNAIDS, MEASURE and FHI guides.

Major indicators coming from HIV/AIDS surveillance are:

- 1. biological:
  - HIV cases;
  - STI incidence;
  - TB cases;
  - Number of AIDS cases in adult people;
  - Number of AIDS cases in children.
- 2. behavioural:
  - sex with high risk in HIV transmission in the last year;
  - using condom during the last sex intercourse with high risk;
  - average age at the first sexual intercourse;
  - drug users who report common use of equipment;
  - number of customers reported by prostitutes in the last week.

## 3. socio-demographic:

- age;
- gender;
- educational and socio-economical status;
- residential or migratory status;
- parity (for pregnant women);
- marital status.

## Using surveillance data

The coordinators of the epidemiological surveillance programmes should be sure that the data collected are due to reach the purpose of preventing and controlling the disease.

Data collected by public health surveillance systems can be used to:

- guide the actions as an answer/response to the events that are important for public health;
- measure the burden of the disease and identify urgent public health problems;
- monitor the evolution of the burden of disease and spot the epidemics or pandemics;
- measure the distribution of the comorbid factors, spot the changes of their distribution and identify the population with high risk;
- document and guide the planning, implementation and assessment of the prevention and controlling programmes of the disease, accidents or harmful exposure;
- assess public health politics;
- spot the changes of medical services offer and their effects;
- facilitate resources for healthcare;
- draw clinical description of the disease;
- serve as a base for epidemiological research.

For HIV/AIDS surveillance to reach the purpose of identifying and implementing prevention measures on target population in order to limit HIV spreading, there should be taken care that the results will be communicated to all potential partners in the preventing and controlling programmes.

Messages should be adapted to the audience (politicians, funds donors, community leaders, risk population) in order that these should understand both the necessity of the intervention and the role of the strategy.

Messages should be brief and clear. Communication should be done by imaging (tables, charts, pictures) that draw attention on the messages.

In order to go on financing the programmes there should be underlined the results that support the success of some previous interventions and there will be recommendations on correcting the aspects that limited the success of other interventions.

The sensitivity of mostly of the data used by HIV/AIDS surveillance systems makes necessary a special attention on confidential aspects. Professional should avoid a social stigmatus when the results are communicated, otherwise the participation of people in surveillance actions is compromised.

Responsibility for services which should diminish the disease burden in afflicted communities is a moral duty for public health services that lead HIV/AIDS epidemiological surveillance. The purpose of the surveillance is to serve the community without touching human rights.

Gathering the data irrelevant in preventing and controlling the disease is not warranted. Thus, collecting the data should be followed by educational, medical and social interventions.

#### Strong points and weak points of HIV/AIDS surveillance systems

Surveillance systems that have been used by now focused on the measurement of HIV infection cases and AIDS morbidity. That allowed epidemics description and successful assessment in national programmes, but without refinements of epidemic dynamics.

The experience of the last decade allowed to identify some strong and weak points, respectively. Thus, the systems still focus their attention on biological surveillance and HIV/AIDS cases reporting, allowing to document the disease burden, resources providing and successful monitoring.

The major limitations derive from the measurement of infection / disease in general population. They do not provide the information to the stakeholders which influence the transmission of HIV in high risk population, warning against the risk of spreading. These populational groups could benefit the most of the interventions made for limiting the spreading.

The strong and weak points are intabulated below:

Strong points	Weak points
Help in generating the	Ignore useful information from other sources (STI, reproduction
public answer on HIV	health)
Help in aiming the	Neglect resources providing in risk population
preventing activities and in	Do not explain the modifications in mature epidemics
planning the answer	Interpreting AIDS cases is hard (35) because of therapeutical
Can monitorize the success	success
of the national answer	Are not flexible
	Surveillance data are not always used efficiently

Table 3 - the strong and the weak points

Source: World Health Organisation Guide (15)

#### Principles of an integrated approach in HIV/AIDS surveillance

Integrated approach in epidemiological surveillance takes into account, generally, the integration of all activities that have to do with epidemiological surveillance into a single service with multiple functions using the same structures, procedures and personnel.

The advantages of this approach are:

- the developped vertical systems can be used as a support and stimulus in less developped systems;
- synergical procedures can use resources in common, improving the efficiency of using them.

The final purpose of the integrated surveillance is to offer:

- complete and high quality information regularly and in time;
- forcasting and spotting epidemics;
- objective assessment of the interventions;
- efficient monitoring of interventional programmes.

The integrated surveillance of diseases has the following features:

- conceives surveillance as an unitary service;
- maintains the control functions of disease together with surveillance;
- recognizes that certain diseases need systems with a higher level of specialization;
- uses a functional approach in disease surveillance;
- does not miss the opportunity of simultaneous development of *essential functions* (collecting, reporting and analyzing the data as well as the answer) and *supporting functions* (training and supervising /coordinating of personnel, improving laboratory capacity, communication, resources management;
- does not need a solution *single system*;
- include the development and improvement of present surveillance networks.

HIV/AIDS is one of the medical conditions that need high specialized systems.

The experience of the last decade in HIV/AIDS surveillance showed on one side the need of a better utilization of outcomes from HIV/AIDS surveillance in order to explain the continuous dynamic of epidemics, and, on the other side of the coin, the need of a better utilization of resources.

Thus HIV/AIDS surveillance uses the concept of integration in a double sense:

- the integration of some elements belonging to HIV/AIDS surveillance in other systems (catching disease surveillance, demographical and national health studies, health reproduction studies, mother and child health programmes, behaviour risk factors studies) with the purpose of taking advantage of synergy; yet, the complexity of the data necessary in HIV/AIDS surveillance is over the informational capacities of a reporting system in catching disease, so that for HIV/AIDS surveillance we need a modular approach;
- the integration of some elements belonging to additional surveillance in the structure of classic HIV/AIDS surveillance systems (behavioural surveillance, STI surveillance, TB surveillance, data about deads, treatment quality and care services audit) with the purpose of increasing the accuracy of surveillance data.

The integration of some additional elements of surveillance, in the structure of surveillance systems used by now represents the strategy recommended by WHO to develop a second generation of systems in HIV/AIDS surveillance for a better use of surveillance data.

The success of antiretroviral therapy in prolonging life for HIV infected persons showed a new dimension of the surveillance data utilization, by estimating the offer for services and the access of HIV positive persons to these services, taking into account clinical and biological criteria in a right way.

Nowadays, the specialists can think over the value of HIV/AIDS cases surveillance defined by unitary criteria on a global scale.

#### Second generation HIV/AIDS surveillance

What is second generation surveillance?

As we already have mentioned, the weakness of HIV/AIDS surveillance systems nowadays generated the need of developping more accurate systems.

Second generation HIV/AIDS surveillance is a WHO concept meant to resolve this weakness and includes the development of modular systems, whose elements can be combined depending on the epidemics stage in each country.

Second generation surveillance does not replace the present surveillance system, but builds up its structures by integrating the already existing systems.

The flexible combination, adapted to the epidemics stage in each country, assures a more efficient use of resources related with needs.

Purposes of second generation surveillance

The new systems have the following purposes:

- Understanding the dynamics of major indicators;
- Understanding behaviour that generates the spreading of epidemics within a country;
- Focusing on high risk population surveillance;
- Assuring flexible systems adjusted to actual needs and epidemics stage;
- Improving surveillance data utilization in order to understand the epidemics, respectively plan the prevention and treatment steps;
- Efficient utilization of resources, stocking them in the right places for acting to reduce HIV spreading, respectively improving patients access to treatment.

Methods recommended in second generation surveillance

Second generation surveillance can be built up on the structure of already existent systems, using all the current methods and adding new ones.

The methods used by mostly of present systems are of biological suveillance:

- sentinel serological surveillance;
- regularly screening of blood and occupational groups, respectively;
- transversal repeated studies in high risk and, respectively general population.

The methods proposed to be added to the present ones in order to increase accuracy and alarm and answering capacities:

- behavioural surveillance studies, quality behavioural and quality transversal repetitive, in general or high risk population, respectively.
- other sources of information: HIV/AIDS cases reporting, STI and TB surveillance, death records.

Principles in leading second generation surveillance

Second generation surveillance is led following fundamental principles with general applicability.

Thus, second generation systems should be adapted to HIV epidemics stage, i.e. to adjust the surveillance model to epidemical situation in each country.

Second generation systems should be dynamic and flexible according to epidemics stage. They should use the resources which could generate the most useful information. For example, aiming high risk population is convenient for a superior impact of interventions.

Second generation systems compare biological data with behavioural data in order to improve the explicite power. Behavioural data play an important role in second generation surveillance representing the key element which adds value in HIV/AIDS surveillance. These can be used to coordinate the process of gathering biological data, explaining the trend noticed in biological surveillance and in reciprocal availability together with biological data.

Second generation systems should integrate information from other sources as STI surveillance, to spot groups with risk in HIV and TB transmission – a possible sentinel population in HIV testing. They should use collected data to improve the national answer to HIV/AIDS epidemics. In this purpose, second generation systems should be used in:

- identifying risk population;
- identifying risk behaviour;
- planning interventions to prevent risk behaviour;
- planning and providing resources necessary in healthcare services;
- measuring national progress in limiting HIV spreading.

Owing the epidemical situation in each country, there are specific recommendations.

# HIV/AIDS stages in different countries

To adjust second generation surveillance systems to epidemical situation of each country, firstly we must define the epidemical situation, using specific criteria.

Following criteria based on dynamic of HIV epidemics, WHO specific guide classifies the epidemical situations of each country in:

- *low epidemic level* Principle: HIV infection evolves within population during years but does not reach significant levels in any populational group. The recorded cases are for individuals with high risk behavioural type suggesting that this is not largely spread in the population or the virus recently entered the population. Numerical approximation: HIV cases > 5% in any populational group;
- concentrated epidemics Principle: HIV infection spreads rapidly into a populational group, but it is not largely spread into general population. This suggests the existence of a network of individuals with behavioural risk. The evolution of epidemics depends on the nature and frequency of relationships among affected and general population, respectively. Numerical approximation: HIV cases > 5% in a population group, HIV cases < 1 % among pregnant women in urban area;
- *general epidemics* Principle: in this stage HIV circulation within general population reaches significant levels. High risk population in HIV transmission maintains its contribution. However, the frequency of sexual behaviour risk remains high enough to transmit virus independently from the contribution of high risk population. Numerical approximation: HIV cases among pregnant women in urban area is constantly over 1%.

These criteria are flexible, allowing each country to evolve from a stage to another.

Surveillance types depending the epidemical stage

Related to HIV epidemics stage in each country, WHO recommends a certain surveillance methodology. These recommendations play an informative role, methodology being adjusted to epidemiological and economical realities of each country.

In some countries, the surveillance systems could be used as alarm systems in HIV spreading.

In these situations, HIV/AIDS should answer the following questions:

- Is there any risk behaviour that could generate an epidemics?
- Which populational group is most exposed?
- How large is this population?
- What behaviour is most risky and how frequent is it?
- What is the relationship between risk population and general population?

HIV surveillance in risk population implies a bundle of ethical aspects. Thus, in reaching the surveillance purpose without harming dignity and fundamental rights, there should be taken into account the following aspects:

- understanding their situation (e.g. social stigmatus);
- assuring access by the agency of community mediators;
- obtaining consent of each individual;
- assuring confidentiality;
- avoiding publicity of results.

The methods recommended for countries with low epidemic level are:

- transversal repeated studies;
- STI surveillance;
- sentinel HIV serological surveillance in risk population;
- HIV/AIDS case reports;
- blood screening.

In countries with concentrated epidemics, we recommend all the abovementioned methods, adding the following:

- transversal repeated behaviour studies;
- sentinel HIV serological surveillance.

During epidemics, HIV circulation is well-known in general adult sexual active population, and heterosexual way of transmission is dominant. In these countries, it is possible that small increase of HIV cases to have a bigger impact on epidemics evolution than a big increase in risk population.

In these countries, HIV/AIDS surveillance systems should answer the following questions:

- Which is the trend in HIV infection?
- How can behavioural trend explain HIV trend?
- Is there any modified behaviour?
- Which behaviour maintains HIV epidemics?
- What impact could have epidemics at individual, familial and national levels?
- In these countries, second generation surveillance purposes could be:
- identifying risk behaviour that maintains epidemics through repeated behavioural studies;
- explaining HIV trend, taking into account the risk behavioural trend through sentinel serological surveillance;

- planning interventions which focus on young populational groups, and improving morbidity and mortality data.
- The surveillance methods used for countries with general epidemics are:
- sentinel serological surveillance among pregnant women from urban and rural areas;
- transversal repeated behavioural studies in general and young populations, respectively;
- sentinel and behavioural surveillance in high risk population;
- HIV/AIDS case reports;
- AIDS mortality data.

Introducting second generation HIV/AIDS surveillance (15)

Second generation surveillance systems are built up on the structure of already existing systems, taking into account the needs of improving the efficacy of the existent systems, and the background of each country.

In a practical way, organizing activities within a national plan, in coherent steps like:

- assessment of the existing surveillance systems;
- national consent on HIV /AIDS surveillance priorities;
- national plan regarding the development of HIV/AIDS surveillance systems;
- surveillance protocols;
- implementing the activities established in surveillance protocols;
- monitoring and assessing the surveillance activities.

## Methodology elements in risk behaviour surveillance studies

Justifying

All over the world, HIV/AIDS epidemics is generated by certain behaviour, that exposes to the risk of HIV transmission. The success of prevention depends on changing this behaviour.

Risk behaviour

This concept means the behaviour that generates a probability for:

- a non-infected person to get in touch with an infected one, and
- HIV infection to be transmitted during the intercourse.

Examples of such behaviour are:

- sexual contact with multiple partners;
- prostitution;
- common use of drug injection.

Examples for HIV infection to be transmitted during the contact:

- condom use;
- presence of other STI;
- anal sex intercourse;
- non-sterile drug injection.

Risk behaviour can be met in special population, being defined by:

- job (prostitutes);
- sexual orientation (homosexuals);
- age (youngsters);
- habits (drug users).

Using the behavioural data

Behavioural data proved to be useful for:

- alarm in HIV spreading in population;
- elaborating and aiming the interventions meant to limit HIV spreading;
- assessment of interventions;
- explaining the trend in HIV infection.

HIV transmission in a population is generated by individual behaviour. Identifying this behaviour as well as its distribution within population helps understanding the mechanism of transmission. Spotting the behavioural changes within a population can warn against the risk of HIV transmission having the chance of intervention before spreading get larger.

Behavioural data can demonstrate:

- what population is on risk;
- which way is transmited;
- which is the risk for general population;
- which behaviour connects the risk population with general population.

These information can lead the intervention programmes through:

- identifying specific intervention;
- focusing the intervention on risk population;
- aiming the behaviour that expose individuals to HIV.

Interventions assessment is necessary to justify the financial aspects of the programmes. During monitorization, a decreased behavioural risk allows successful documentation for protective behaviour.

Changing behavioural risk leads to a lower number of new infections. We can correlate the efforts in reducing the behavioural risk with reduction of the number of cases. If the behavioural trend has no relationship with the number of cases, then the dynamic of cases cannot have anything to do with interventions, but other factors are involved (36):

- AIDS increased mortality;
- Changes in population dynamics (37);
- Selection and measurement errors.

Methods for data collecting

Gathering of data is done supported by various behavioural studies, qualitative and quantitative.

Qualitative behavioural studies allow risk behaviour identification within a population, and helps understanding the way of spreading among the members. They allow a deep approach of the problem on a small, non-representative group of persons, through direct methods - experimental and observational, or indirect methods – focus groups, experts analysis, case studies, but it cannot help measuring the trend.

Quantitative behavioural studies are transversal studies of risk behaviour on representative groups from target population, regularly repeated. They are led on representative trade groups belonging to general population, and provide standard data that could be compared during the time. The patients are, generally, compliant. However, the high costs limit their repetition.

They are recommended for countries with general epidemics. In countries with low level of resources, they are integrated in HIV / sexual behaviour modules, in larger demographic or national health studies.

Behavioural surveillance studies are transversal and repeated. The frequency of data aquirement depends on prevention programmes implementation.

The main feature of these studies is consistency, i.e. using standard methods, assuring comparison of data.

Surveillance studies focus their attention on populational groups and behaviour that have a definitory contribution in HIV spreading. These are useful in epidemics concentrated in risk population.

Behavioural data value

The value of data depends on their availability. The availability of data regarding behavioural risk reported by a suject is still doubtful (38).

Recent experience proved that, as a rule, people do not lie. However, when it is about a stigmatized behaviour, this is expected to happen. Thus, the honesty of the reporting person depends on how much attention pays to the following aspects:

- confidence;
- personal qualities and interviewer attitude;
- the way to ask questions.

To make data available, we should compare them with data from other sources. Nowadays, there are lots of studies that demonstrates the similarities between sexual behaviour data and biological indicators of sexual activity (pregnacy, STI).

To conclude, though reporting cannot be eliminated, behavioural data remain useful for behavioural risk trend surveillance.

Data availability is, in turn, influenced by the gathering manner. Thus, there is recommended to avoid collecting data from individuals selected for serological testing. Yet, to guarantee the comparison of results – studies versus biological surveillance, there is recommended that the groups should be selected from the same population. However, a minimal socio-demographic variation is recommended in comparing groups features.

Using data to justify how a behaviour changed because of an intervention is another precious element of behaviour surveillance. Nevertheless, finding a single change does not allow a causal link between this one and the intervention. But behaviour change, together with indicators of intervention allow the deduction of a plausible effect, because of the intervention.

Steps in organizing behavioural surveillance studies

Managing behavioural surveillance studies needs to follow some steps to succeed - Family Health International Guide cited by WHO.

*Choosing partners.* All stakeholders should be identified, as a technical working group that meets periodically in order to establish purposes. Such partners could be: public health and other governmental institutions officials, non-governmental organizations which deal with risk communities, risk communities and the ones that get in touch with their members, funds donors in order top revent HIV, etc..

*Agreement.* This time, the identified partners from the previous step should agree with the following aspects: what population groups will be taken into account, what kind of information will be collected, who will collect and analyze data, which way data security will be provided and how they will be used in people interest.

*Choosing population groups.* Ideally, population is chosen following these technical and practical criteria: contribution in HIV transmission, existence of an intervention plan, political stage, resources, accessibility. There is recommended this to be followed by a rapid assessment of behaviour in the population they have chosen.

*Defining objectives, indicators.* This time, the organizers should establish clearly: what aspects do they want to know to establish the objectives, how do they want to measure these aspects to define the indicators that will be used in progress assessment, etc..

To reach the HIV transmission prevention purpose a programme should have three categories of general objectives:

- intervention should aim the population;
- intervention should reach the individuals in the population;
- individuals should change their risk behaviour.

There are defined indicators for each category. The first two are to assess the process of HIV/AIDS prevention programmes.

The indicators of behavioural surveillance focus on risk behaviour assessment impact in HIV transmission because, finally, the success of prevention depends on risk behaviour changing.

Behavioural changing is made gradually. Having a new behaviour means:

- having knowledge regarding HIV infection;
- having a correct concept and attitude.

Thus, in order to monitor risk behaviour and assess behaviour indicators, there should be measured both risk behaviour and generator factors (knowledge, attitude). In order to elaborate a behavioural indicator, we must define the following factors:

- numerator;
- denominator;
- time period;
- what is measured;
- explaining some terms (e.g. defining group affiliation).

To assure comparison of measurements during the time and in real tridimensional space, we recommend to standard the indicators used.

*Defining populational groups to work with.* This time, some groups from target population should be defined taking into account technical aspects in analyzing surveillance data.

Universe = population whom results can be attributed according to its representativity.

Field = segment of population for the indicators to be estimated. Into this respect, there is necessary to choose a group for each field, and to avoid an insufficient number of individuals.

There also should be defined the individual affiliation to the above mentioned groups.

There should be established geographical limits of target population (national, regional, territorial, local). There is recommended these to be the same with the ones where surveillance is organized.

*Selecting places.* Taking into account that special population groups are targeted, there should be identified access point to these groups. Once identified, these should be listed and spotted on the map. Moreover, investigators must estimate the number of individuals available in each place. Finally, the places will be selected taking into account the abovementioned data.

*Building up the backgroud for choosing groups.* This step superposes on the previous one. It includes making up of a list with places and individuals from each site.

*Establishing the way of choosing groups.* The recommended model in the guide is choosing nests. This is a technical exercise that means:

• defining universe and field;

- how big is the group;
- how big is a nest.

This needs the following data:

- risk behavioural level;
- minimal magnitude that should be measured when behaviour is changed;
- measurement accuracy.

The model should include implementation instructions.

*Protocol.* As a consequence of the abovementioned cascade of steps, a protocol should be established. This includes all the methodology of the study, structured as followed:

- Purposes;
- Objectives;
- Methodology;
- Data collecting instruments;
- Guides for interviewers and supervisors.

*Pre-testing the instruments for collecting the data.* Concerning the data aquisition, there are recommended standard questionnaires, in order to compare the data. A pretesting is mandatory and should be followed by questionnaires adjustment according to the identified problems.

*Interviewers training.* When the final form of the questionnaire is ready, the interviewers should be trained. This aspect is very important for the quality of the collected data, because the attitude of the interviewer could influence the answers. When recording the answers, procedure codes should be followed.

*Collecting data.* During data aquisition, the interviewers should be watched over and the questionnaires should be verified to be filled correctly and accurate.

The main investigator should coordinate and supervise the whole process.

Addition of codes should be done rapidly, by a single person. When this is not possible, we recommended no more than three persons.

*Data management.* When collected data are available, they are transferred from paper to magnetic support, taking into consideration the following aspects:

- how accurate they are;
- if they respect the limiting values;
- if there are missing data.

*Analyzing data.* The value of data analysis depends on the previous steps. Actually, this step mainly spots:

- calculating the indicators;
- group importance;
- computing standard errors of estimated values;
- testing the trends' statistical significance, or the differences among various groups. Using data – connecting HIV/AIDS cases trend with behavioural changing.

The whole effort of collecting the data should finalize with their utility in reaching the purposes of disease prevention and programmes control, including educational issues.(39) Into this respect, the responsibility belongs to the public health authorities. The trends and behavioural risk changes should be correlated with the number of HIV/AIDS cases.

# Exercises

## Task 1:

Students are required to present structured lectures about the general objectives and methods in HIV/AIDS surveillance. Particular attention should be paid to stories of success in this field.

# Task 2:

Trainees and students are required to take part in debates, as protagonist/antagonist and in the audience, respectively. The lively yet balanced discussion on controversial issues concerning general objectives and methods in HIV/AIDS surveillance will generate ideas through progress.

# Task 3:

Students are required to participate in how-to sessions, a unique opportunity for intense interaction between a limited audience and two ir three experts in fields of HIV/AIDS surveillance.

# Task 4:

Students are encouraged to interact closely with nurses and laboratory technicians, under the coordination of a specialist, in order to develop practical skills in HIV/AIDS surveillance field.

#### **Recommended readings:**

- 1. Topics in HIV Medicine, July/August 2003,11(4):140-4.
- 2. 2003-2008 HIV Prevention Community Planning Guidance, CDC Center for Diseases Control and Prevention.
- 3. Setting HIV Prevention Priorities: A Guide for Community Planning Groups, March 2005, AED, Center AIDS & Community Health.
- 4. HIV Prevention Community Planning: An Orientation Guide, January 2005, AED, Center AIDS & Community Health.
- 5. HIV Prevention Strategic Plan Through 2005, January 2001, CDC Center for Diseases Control and Prevention.