

Regional Consultation on HIV epidemiologic information in Latin America and the Caribbean: Surveillance for an enhanced HIV and STI response

Preamble

Since the beginning of the epidemic countries quickly included AIDS case reporting in their routine surveillance systems. The introduction of antiretroviral treatment has delayed the onset of AIDS with increased survival for people with HIV. This has led many countries to begin surveillance of HIV infection alongside with that of AIDS.

Since 2000, countries have focused resources and attention on implementing HIV second generation surveillance with special studies among key populations. After three decades of the HIV epidemic, international recommendations on surveillance, monitoring and evaluation have progressed substantially in-line with advances in scientific knowledge and response to HIV.

In 2003, one of the first regional meetings on HIV surveillance (LAC Epi-Network) took place in Havana, Cuba, where the concepts of 2nd generation surveillance were discussed and its application agreed upon throughout the countries of the region as well as the integration of different information sub-systems. This meeting was followed by another in Rio de Janeiro in 2005, where there was in-depth analysis of the epidemiological situation of HIV at the regional, sub-regional and national levels that showed progress on available information on HIV in LAC.

The goal of the regional consultation was to follow up on recommendations agreed upon in the abovementioned previous regional meetings, define priority areas for HIV epidemiologic information in LAC, with a main focus on HIV and STI surveillance and program monitoring, address challenges and propose avenues for action to accelerate the closing of key health sector information gaps. Consultation experts were invited from 30 Latin America and Caribbean countries, civil society, and Centers for Disease Control and Prevention, Public Health Agency of Canada and United Nations Organizations.

Recommendations regarding HIV case based surveillance

Experts from the participating countries agreed on the importance of conducting HIV case based surveillance using a longitudinal perspective, collecting information on HIV cases and sentinel events throughout the course of HIV infection. HIV case surveillance presupposes an initial case report with subsequent updates. For this, Participants from countries agreed that the use of unique case identifiers is a requisite. These unique patient identifiers can be developed by incorporating additional variables to named-based reporting. If name-based reporting is used appropriate measures should be in place for protection of the data.

Having a unique case identifier facilitates the integration of information from different data sources (surveillance, laboratory, pharmacy, vital statistics). This allows the longitudinal tracking of HIV cases and improves the quality and completeness of the information throughout the cascade of sentinel events.

Additionally, Participants from countries agreed on a single regional definition of an HIV case: "any new HIV diagnosis regardless of the clinical and immunological stage." The diagnosis of an HIV infection will be determined by each country's diagnostic norms and standards.

Participants from countries recommend the incorporation of viral load and CD4 surveillance as part of HIV case based surveillance.

Participants recommended a minimum set of variables to be considered essential and common across countries. These variables are presented in Table 1.

Table 1. Minimum Variables for HIV Case Surveillance
Socio-demographic variables, such as : Unique identifier (name, ID, etc...) * Date of birth Biological sex Place of residence
Variables on diagnosis and reporting Reporting date Notifying unit Diagnosis date
Risk behavior variables and risk factors** , variables that look at sexual behavior (not sexual orientation), injecting drug use, exposure to transfusion, perinatal transmission. Exchanging sex for money or other goods. Etc... With the variables on risk behaviors and using standard algorithms the transmission mechanism categories can be developed.
Immunologic, virologic and treatment variables ** CD4 Viral load ARV start date
Variables on vital status** Date of death

* countries should consider the development of a common unique code adapted to national context.

** The collection of these variables can be done after you notify the HIV case.

There were additional recommended variables such as gender identity (male, female, transgender), ethnicity, education level as a marker of socioeconomic status, nationality, migration status, drug use, TB and pregnancy.

AIDS surveillance was recommended as a reportable event within HIV case based surveillance. Surveillance of AIDS cases is useful in the assessment of timely access to diagnostic and treatment service.

Experts agreed that ensuring the quality and functionality of HIV case based surveillance systems requires greater interaction between surveillance, services, pharmacy, laboratory, and vital statistics (mortality) information systems. Therefore participants highlighted the following as required essential elements in order to have functional surveillance systems: appropriate political

support, protocols and standard operating procedures that promote information integration with interdisciplinary work, and integration of civil society members in the advocacy and planning of such systems.

Strengthening and training of human resources at different levels on roles and responsibilities is recommended as a key element to improve functionality of the case surveillance system and quality of the case surveillance data. For example, training on how to collect accurate data on risk behaviors from clients in a culturally appropriate and respectful manner is recommended. Participants also recommended strengthening integration with community-based service providers working with vulnerable key populations for data collection. It is also necessary to ensure capacity in analyzing HIV case surveillance data (longitudinal analysis) among epidemiologists and statisticians, including the ability to link data from different information systems, in working with relational databases, and for the development of appropriate analysis and dissemination of information. It is also recommended that the surveillance system include systematic quality improvement procedures.

All countries collect data on HIV diagnosis among children, but challenges persist in the surveillance of exposed children. It is therefore recommended to strengthen the monitoring of the mother-infant pairs through increased collaboration with MCH services, and to promote auditing cases of children with HIV.

As information systems (physical and electronic) improve so should the security and confidentiality to protect these sensitive data. The data protection measures need to be in place from the facility-level to the national-level.

Strategic information for HIV care and treatment programs

The meeting proposed a monitoring framework for HIV programs based on the concept of "continuum of care" presented as a cascade from diagnosis, linkage to care and treatment, retention in care and treatment, and viral load suppression. This framework is a tool to support the implementation of the Treatment 2.0 Initiative which should strengthen program monitoring and is based on a reorganization of existing indicators. Monitoring the cascade is useful to identify gaps in services for individual level care and as well as population level impact (reduced morbidity, mortality and incidence).

Participants from countries agreed on the usefulness of this framework to identify gaps in the information systems and the different stages of the cascade regarding access, coverage, retention and quality of services. It also presented a proposal of indicators to monitor the "cascade" of continuing care that participants analyzed in relation to relevance and feasibility.

The participants accepted and recognized the value of the key indicators of the "cascade" of the continuum of care, highlighting the need to develop specific definitions of the numerators and denominators.

Participants from countries also stressed the need to strengthen the capacity to link data between different information systems. Finally, they also recommended assessing the cascade (access, coverage and quality of care) for key populations, including MSM, SW, IDU, and others.

Participants from countries highlighted the need for global entities to harmonize the indicators to reduce the burden of reporting regarding AU, GARP, ARV surveys, IAT, HIV-TB and the Elimination Initiative of HIV mother to child transmission.

STI surveillance

STIs are reported in most countries of the region, however there is wide diversity in terms of laboratory capacity and reporting methods, and little standardization. With advocacy, clear guidelines and capacity building, however, country experts agreed that routine reporting can be improved.

Participants reviewed WHO-proposed STI surveillance indicators in terms of importance and feasibility, and identified priorities, gaps and needs for strengthening routine STI reporting systems. All groups agreed that case reporting of gonorrhoea, syphilis and congenital syphilis (as STI aetiologies) and urethral discharge and genital ulcer disease (as syndromes) is feasible. Participants also agreed to routine monitoring of syphilis prevalence among pregnant women, and most also supported it among sex workers and MSM although many Participants from countries indicated that clinical services for these populations are lacking. Participants from countries identified challenges in diagnostic testing for STI. Recommendations were made for strengthening lab services, human resources and data analysis. PAHO was requested to support countries with advocacy and clear guidelines to strengthen STI surveillance systems.

Integrating information from different sources: prevention of the mother to child HIV transmission and TB-HIV

This session reiterated the importance of the linking of information systems addressing examples in the field of prevention of mother to child transmission of HIV and congenital syphilis and tuberculosis and HIV.

Key areas for improvement are strengthening of coordination, linking data systems including data exchange and joint analysis between maternal health programs, child and HIV, and TB and HIV. Also monitoring of the progress of implementation of the collaborative activities of TB-HIV was recommended.

Surveillance and monitoring among key populations

Participants recommend surveillance of key populations to track the epidemic, guide policies for policy and care/treatment and allocate resources.

Current HIV case surveillance systems collect information on the number of cases, socio-demographic characteristics on key populations however the quality of the data vary across countries.

The collection of behavioral risk data needs to be improved by standardizing the variables collected and training of providers on the solicitation of the information. As previously mentioned, in HIV case surveillance systems, countries may want to consider collecting data on transgender.

To fill the information gaps special studies are needed to provide information on HIV prevalence, risk behavior, knowledge, attitudes and practices, social determinants of health, and

comorbidities. These data should be triangulated with the information from HIV case surveillance to give a more complete picture of the epidemic among key populations. Countries with smaller populations may want to prioritize the collection of data on key population in HIV case-based surveillance.

Participants from countries noted that conducting periodic surveys among key populations is challenging given the cost of the surveys, the skilled human resources needs and the lack of funding from host governments to conduct the surveys. Currently these surveys are conducted through external funding and are not a line item in country budgets.

Nevertheless, participants recognized the need to improve the strategic use of this information; the importance of information in key populations is needed to guide public policies for prevention, diagnosis, care and treatment by the national programs, and in some countries also for reorganizing health services.

Another challenge is disseminating information on key populations by government planners as well as to the key population of interest.

Information provided by community based organization projects and NGOs can add important additional information to routine systems and special studies including how to work with key populations.