MEETING REPORT

Regional consultation on HIV epidemiologic information in Latin America and the Caribbean

Quality surveillance data for an enhanced HIV and STI response

Panama City, Panama, 7-9 November 2012

DRAFT FOR REVIEW

MEETING REPORT

Table of Contents

Executive Summary

Experts from Latin America and the Caribbean and the United States and Canada came together for three days to discuss and advance key recommendations towards surveillance and monitoring of HIV infection with the ultimate goal of improving the Region's response to the HIV epidemic.

The consultation included experts from 27 countries of the Region as well as international organizations active in the region. The participants were health officials in charge of HIV surveillance in the PAHO member States, as well as representatives of UN agencies involved in the HIV response (PAHO / WHO, UNAIDS, UNICEF, UNFPA), the Centers for Disease Control and Prevention of the United States' (CDC), Health Focus-GIZ, the Organization of Eastern Caribbean States (OECS), COMISCA, ORAS and NGOs.

During this meeting, the participants discussed priority areas of epidemiological information on HIV and other sexually transmitted infections (STIs), and identified the actions necessary to close information gaps. The main consensus areas and recommendations are:

• HIV surveillance should be based on cases of HIV infection (rather than AIDS cases) and should follow the evolution of each case over time. This is termed the "longitudinal approach".

• The standard definition of a case must be "all new HIV diagnosis regardless of clinical and immunological stage".

• The unique case identifiers should be used to facilitate longitudinal monitoring and the integration of information from different sources (health services, laboratories, pharmacies, vital statistics).

• Specific measures should be established to protect patient confidentiality and data security in systems using name-based records.

• Data should be collected for a minimum set of standardized variables, including risk behaviors and factors (such as sexual behavior, injecting drug use and exposure to transfusion) and immunological variables and treatment (such as viral load, CD4 count and initiation of antiretroviral therapy).

• Technical cooperation organizations and donors should harmonize indicators used in order reduce the burden of reporting, facilitate research and analysis, and promote the sharing of information and experiences in the surveillance, prevention and care of HIV.

• Monitoring/surveillance should include aspects and assessment of access and quality of care across the continuum of care, ranging from diagnosis to entry into care and treatment, retention in care and treatment, and control of viral load.

• Special attention should be given to key populations such as men who have sex with men, sex workers and injecting drug users.

• The monitoring of exposed children should be strengthened through better monitoring of mother and infant pairs in coordination with maternal and child health services.

Participants also called for an expanded training and human resource development in areas such as eliciting sensitive information (how to collect data on risk behaviors) in a culturally appropriate and respectful, as well as statistical and epidemiological analysis of surveillance data using a longitudinal perspective, among others.

Context

The region of Latin America and the Caribbean (LAC) has mounted one of the most significant responses to HIV in terms of antiretroviral therapy and prevention of mother-to-child transmission among middle and low income countries.[1] Since the beginning of the epidemic, countries quickly included AIDS case reporting in their routine surveillance systems and most have advanced towards HIV case based reporting. LAC also made early progress in implementing HIV second generation surveillance with special studies among high-risk populations.[2-4]

After three decades of the epidemic, international recommendations on surveillance, monitoring, and evaluation have progressed substantially in line with advances in scientific knowledge and response to HIV.[5-8] Progress made by health services in response and systematic data collection has also led to changes in surveillance needs and the imperative to move towards integrating information systems.[20-23]

In 2003, a regional meeting on HIV surveillance took place in Havana, Cuba, where the concepts of second 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 an in-depth analysis of the epidemiological situation of HIV at the regional, subregional, and national levels that showed progress on available information on HIV in LAC.

We are currently in a transition phase in programmatic management based on public health principles, the consolidation of HIV infection as a chronic disease, and the need for greater integration drawing from different information sources on HIV. WHO has developed new recommendations on updating and evaluating second-generation surveillance systems; HIV case-based surveillance; guidelines for monitoring most at risk populations; the use of tests and algorithms to estimate population level incidence of HIV infection; and surveillance of HIV drug resistance.[24-32] We would like to take advantage of progress in programmatic areas (treatment, prevention of mother-to-child transmission, and HIV testing and diagnosis), as well as progress in international data review and reporting in order to strengthen and integrate information systems at the national level.

This regional consultation had the goal of following up on recommendations agreed upon in previous regional meetings, fostering further progress in priority information areas in LAC, and addressing challenges and proposing avenues for action to accelerate the closing of the information gap. To this end, the objective set out below was proposed.

Surveillance of sexually transmitted infections (STI) in the region has strengths (such as existing national surveillance systems in many countries for routine reporting of the most important STIs (e.g. syphilis and gonorrhea); monitoring of syphilis in pregnant women, and certain sentinel surveillance programs in STI clinics. Despite this, there had never been a regional consultation on STI surveillance to review existing gaps and promote improved harmonization of STI surveillance in the region.

Objectives

The general objectives were:
a) review the current situation of available epidemiological information for HIV and STI
b) identify priority areas for LAC for strengthening strategic information in the health sector for HIV and STI
c) reach a consensus on recommendations for improvement in the identified priority areas.

Aspects of availability, quality, analysis, and use of epidemiological information were addressed during the meeting.

Outcomes and Results

- Consensus declaration on the strategic priority areas for strengthening of surveillance and other information systems related to the response to the HIV/STI epidemic.
- Increased participant knowledge on the international recommendations in the realm of HIV strategic information mainly focused on surveillance.
- Participant commitment to move towards common priority goals discussed during the meeting.

HIV case based surveillance and review of the situation in the region

The main concepts on HIV case based surveillance were presented. There was discussion on the relevance of the proposed approach and agreed that an integrated information system with a unique case identifier would maximize the use of existing information for monitoring HIV infection.

The day ended with a roundtable discussion on the latest developments in methodologies to measure HIV incidence and practical experiences with calculating the national HIV incidence rates in the United States and Canada. These experiences combined the use of specific laboratory tests with data from HIV case reporting systems.

Strategic information for care and treatment programs

Dr. Massimo Ghidinelli introduced PAHO's proposal on Treatment 2.0 surveillance and monitoring. The framework for monitoring health care services is based on the concept of a continuum of care as shown in the "HIV treatment cascade" diagram. People living with HIV can maximize the benefits of antiretroviral therapy (ART) if they are aware that they are infected, have access to HIV treatment and antiretroviral therapy, and adhere to that treatment. Antiretroviral therapy suppresses viral load with the attendant benefits for the patient as well as for control of the epidemic. Scientific evidence has shown that antiretroviral therapy has become increasingly potent, better tolerated, and less complex. As a result, people living with HIV who are in treatment can have undetectable plasma HIV RNA levels. However, deficits in the continuum of care beginning even before the HIV diagnosis, lack of linkages with health care services, problems such as retention in care, delayed access and lack of adherence to antiretroviral therapy, and gaps in the provision of antiretroviral drugs are barriers to optimal outcomes, successful program implementation, and reductions in HIV transmission.

In order to reduce potential deficits in the continuum of care, 35 priority indicators were presented related to HIV testing, linkage to care, treatment, adherence and retention, and viral load suppression. This framework was accepted and the indicators were discussed in working groups, where most were classified as high priority. Only six out of the 35 were classified as of lesser priority, some of these also involved greater difficulties in measurement. The groups discussed operational difficulties in obtaining such information and offered suggestions for improvements. Developing and/or reviewing the indicator technical description sheets was also highlighted as an important step to support the use of these indicators (see Annex 1 and Box 1).

HIV drug resistance surveillance

In 2012, the World Health Organization published the first global report on HIV resistance to antiretroviral drugs and reiterated the need to include drug resistance monitoring in national HIV surveillance plans.[1]

This follow-up included a presentation on the new WHO recommendations on monitoring HIVDR at the global level, with a specific focus on their implementation in countries with concentrated epidemics. The basic guidelines and specific public health objectives of four surveillance protocols were presented: surveillance studies on transmitted resistance among recently infected individuals; cross-sectional surveillance studies on resistance among individuals who initiate antiretroviral therapy; cross-sectional

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[1] The WHO global report is available from:
http://www.who.int/hiv/pub/drugresistance/report2012/en/index.html

surveillance studies on acquired resistance among individuals in antiretroviral therapy; and studies on initial resistance among recently diagnosed children under 18 months of age.[2]

The most recent version of the WHO recommended Early Warning Indicators (EWI)[3] for the prevention of HIVDR was presented. The 2012 EWI evaluate antiretroviral prescription practices—especially in mono- and biotherapy—, retention in treatment, timely drug recall, shortage events, and viral load suppression. Emphasis was placed on the importance of using these indicators as a management tool in order to enhance quality of care in clinics providing antiretroviral therapy at the local level.

STI management and control

Dr. Richard Steen reviewed the status of STI surveillance in Latin America and the Caribbean and the WHO proposal on STI surveillance. This proposal is described in detail in the WHO's new STI surveillance guide.[4] Dr. Steen explained that two key components of STI surveillance are: case (and/or syndrome) reporting and programmatic data on STI prevalence among pregnant women and key populations.

In working groups, the participants discussed the feasibility of having these basic surveillance components in place in their countries. They identified important gaps in existing STI surveillance systems and proposed solutions and improvements. The participants also discussed the relevance and feasibility of the WHO's proposed STI epidemiological surveillance indicators.

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.

All the groups agreed that case reporting of gonorrhea, syphilis, and congenital syphilis (as STI etiologies) and urethral discharge and ulcerative genital 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, which hampers surveillance.

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.

Linkages among information systems

Dr. Priscilla Idele of UNICEF presented the global monitoring framework for the Initiative for the Elimination of Mother-to-Child Transmission of HIV. Next, Dr. Gerson Fernando reviewed the epidemiology and response to mother-to -child transmission of HIV and congenital syphilis in Brazil, as well as the national strategies and approaches in place in that country.

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[2] Additional information on the generic protocols of the HIVDR surveillance strategy is available from: http://www.who.int/hiv/topics/drugresistance/protocols/en/index.html

[3] The new guide with the technical sheets for EWI is found on the WHO website: http://www.who.int/hiv/pub/meetingreports/ewi_meeting_report/en/index.html

[4] Available in English from: http://www.who.int/reproductivehealth/publications/rtis/9789241504478/en/index.html

With regard to linkages between HIV and TB activities and information systems, Dr. Lopez Olarte presented the progress made in collaboration and indicators on TB-HIV coinfection. As an example of this, Dr. Sorto presented El Salvador's experience in strengthening linkages between information systems that monitor collaboration on TB/HIV.

Surveillance and monitoring among key populations and poster exhibit

Posters were used to share the findings of the HIV surveillance study among key populations in twelve countries. The posters covered topics such as how each country obtained information on key populations, their findings, and how they used and disseminated this information. In sum, it was clear that all the countries have studies on key populations such as MSM and that there are several information sources that would facilitate a more integrated analysis and data triangulation. The countries also faced a common challenge in establishing trends in behavioral variables and HIV prevalence among key populations.

Strategic information for investment sustainability

Achieving the goal of zero new infections, zero discrimination, and zero AIDS related deaths is now a world priority and strategic thinking and investment are required to ensure a sustainable response to HIV. This requires a comprehensive approach to strategic information as critical to an efficient and sustainable response by making the link between epidemiological surveillance, resource tracking, and the investment framework (IF). The IF—including models and tools for resource tracking and mobilization—is a key component of strategic information. Experiences in the application of the IF in Latin America and the Caribbean were shared in order to broaden the concept of what ¨strategic information¨ is and its usefulness in times of growing financial limitations. The aim was to answer the following questions: What strategic information is needed in order to develop investment plans and sustainable interventions? How can a road map be developed to ensure sustainability in times of financial constraints? Trends in Latin America and the Caribbean were examined in terms of external financing, Gross Domestic Product, national ownership of the response, public investment in the response to HIV, and dependence on external sources for antiretroviral drug purchases. Jamaica carried out the National Aids Spending Assessment (NASA), the Modes of Transmission (MOT) exercise and the sustainability study and linked them to the National Strategic Plan in order to identify priorities, costs, and gaps. With these inputs, the country is developing a sustainability strategy premised on services integration and decentralization, transaction cost reduction, and evidence-based strategic investments in key populations and interventions. The Regional Coordination Mechanism in Central America, Belize, and the Dominican Republic has developed a sustainability strategy and road map for reducing financial vulnerability by optimizing the use of available resources (including joint negotiation and purchases of ARV, tests, condoms and other crucial supplies for treatment and prevention) and defining innovative alternatives for additional financing.

Recommendations and Proposals from the Meeting

Recommendations for HIV case based surveillance
a. 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 natural or modified course of HIV infection. HIV case surveillance presupposes an initial case report with subsequent updates. For this, participants from the countries agreed that the use of unique case identifiers is a requisite. These unique patient identifiers can be developed by incorporating additional variables to name-based reporting.
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.

b. 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.

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

d. The experts from the participating countries in the region recommended a minimum set of variables to be considered essential and common across countries. These variables are presented in Table 1.

Conclusions and Recommendations

Table 1. Minimum variables for HIV case based 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 (transactional sex). Etc.   With the variables on risk behaviors and using standard algorithms, the transmission mechanism categories can be developed.
Immunological, 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 the HIV case is reported.

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

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

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.

    g.   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 the quality of case surveillance data. For example, training health care providers on how to collect accurate data on risk behaviors from clients in a culturally appropriate and manner is recommended.

    h.   Participants also recommended strengthening integration with community-based service providers working with vulnerable key populations for data collection. It is also necessary to

Conclusions and Recommendations

ensure capacity in analyzing HIV case surveillance data (longitudinal analysis) among epidemiologists and statisticians, including the ability to link data from different information systems, work with related databases, develop appropriate analyses, and disseminate information.

i. It is also recommended that the surveillance system include systematic quality improvement procedures.

j. 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 mother-infant pairs through increased collaboration with maternal and child health services, and to promote auditing cases of children with HIV.

k. As information systems (physical and electronic) improve, so should the security and confidentiality to protect these sensitive data. Effective 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 in the region of Latin America and the Caribbean, 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 as well as population level impact (reduced morbidity, mortality, and incidence of new infections).

a. 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. A proposal of indicators to monitor the "cascade" of continuing care was presented and participants discussed its relevance and feasibility.

b. 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.

c. Participants from countries also stressed the need to strengthen the capacity to link data between different information systems.

d. Finally, they also recommended assessing the cascade (access, coverage and quality of care) for key populations, including MSM, SW, IDU, and others.

e. Participants from countries highlighted the need to harmonize the indicators to reduce the burden of reporting regarding AU, GARP, ARV surveys, IAT, HIV-TB, Elimination Initiative.

Conclusions and Recommendations

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 epidemiological surveillance indicators in terms of importance and feasibility.

a. All groups agreed that case reporting of gonorrhea, syphilis, and congenital syphilis (as STI etiologies) and urethral discharge and ulcerative genital 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, which hampers surveillance.

b. 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.

Linking mother and child and TB-HIV data
This session reiterated the importance of linking information systems, addressing examples in the area of prevention of mother-to-child transmission of HIV and congenital syphilis, and tuberculosis and HIV.

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

Surveillance and monitoring among key populations
Participants recommend surveillance of key populations to track national epidemics, guide policies for prevention, care, and treatment, and allocate resources.

Current HIV case surveillance systems collect information on the number of cases and the sociodemographic characteristics and geographical distribution of cases among key populations (MSM, SW, IDU, etc.), the quality of the data varies from country to country.

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

b. To fill the information gaps, specials studies are needed on HIV prevalence, risk behavior, knowledge, attitudes, and practices, social determinants of health, and comorbidities among these populations. These data should be triangulated with information from routine surveillance systems with more reliable data on key populations to give a more complete picture of the epidemic. Countries with smaller populations (less than 500,000 inhabitants) may want to prioritize the collection of data on key populations in HIV case-based surveillance.

Participants from countries noted that conducting periodic surveys among key populations is challenging given the cost of the surveys, frequent dependence on international funds, and the lack of national

Conclusions and Recommendations

budget allocations to conduct them on an ongoing basis. They also described operational problems such as difficulties accessing these populations, a shortage of trained human resources at the community level and of technical human resources at the program level to support implementation, and limitations in terms of representativeness, quality, and the use of standardized methods over time.

c. Participants recommended improving the strategic use of this information. They underscored its importance for guiding public policy on prevention, care and treatment by national programs, for reorganizing health services in some countries, and for drafting funding proposals for national, international and bi- and multilateral donors.

d. Another challenge is improving dissemination of the information, making sure, in particular, that it reaches important recipients such as the key populations and government planners.

e. Participants also recommended involving community-based organizations and NGOs, since they can add important additional information to routine systems and special studies, including the actual access of these populations to the services network.

Agenda

Time	Topic	Format/Description	Responsible
7:30-8:00	Registration/document collection		
8:00-8:45	Introduction, welcome Objectives		Ministry of Health PAHO PWR-PAN M. Ghidinelli—objectives
8:45-9:15	Summary of recommendations for 2nd generation surveillance and status of epidemiological information and surveillance systems. 20'	Presentation/Summary of the new recommendations and review of agreements from the last regional meeting, considering also subregional meetings Review of status of surveillance systems	Txema García Calleja WHO
9:15-10:15	HIV case based surveillance recommendations. Concept. What information elements are key for case surveillance? Including specificities such as: a) HIV case surveillance for mother-to-child transmission in the context of the Elimination Initiative and how to handle them. b) VL and CD4 surveillance: uses and applications.	International recommendations 20' Country example: Haiti 15' Country example of integration of laboratory data and case based surveillance (laboratory and CD4, CV): Brazil 15' Questions and answers 10	Irum Zaidi (CDC-GAP Atlanta) MOH Haiti MOH Brazil
10:15-10:30	Organization of group work: explanation of the questions	Group work. Discuss with your group achievements and barriers (and possible solutions). Prepare 2 slides (one for each question)	Facilitator Explanation of group work 10'
10:30-10:45	Coffee break		
10:45-13:00	Addressing the HIV case based surveillance from a longitudinal perspective: What modifications do you need to make to have a functional HIVCBS? What are the barriers in your country for a functional	Break out groups Sub regional groups Facilitator summarizes consensus and disagreements. *Working group exercise number 1*	Group work

Agenda

Time	Topic	Format/Description	Responsible
	HIVCBS? What are the barriers in your country to appropriately determine mother to child HIV transmission rates? Is surveillance of VL and CD4 feasible in your country and if not what solutions can you envisage?		
13:00-14:00	Lunch		
14:00-15:00	Groups report back to plenary	Each group 10' Plenary discussion 20'	
15:00-15:30	Coffee break		
15:30-16:30	Round table on Measuring HIV incidence and applications for surveillance	HIVCB reporting and estimating incidence: USA example: A. Hernández 20' Canada example: Chris Archibald 20' Reporting on WHO HIV incidence working group: T. Garcia Calleja 15'	Chair: Txema García Calleja. WHO A. Hernández (CDC, Atlanta) Chris Archibald(PHAC, Ottawa)

Day 2. Thursday November 8th, 2012
Rapporteur: Maxia Dong, Eldonna Boisson, Paul Edwards
Facilitators: Patricia Bracamonte (morning), Irum Zaidi (afternoon)

Time	Topic	Format/Description	Responsible
8:30-12:30	Strategic information for treatment programs		
8:30-9:00	Surveillance and monitoring for Treatment 2.0	Presentation: 15'	M. Ghidinelli (PAHO)
9:00-9:30	HIV drug resistance surveillance (HIVDR)	Presentation: 20' New WHO recommendations for HIVDR (transmitted, pre-ART, acquired and initial) and their application in the Region. Questions and discussion 10'	G. Ravasi(PAHO)
9:30-12:30	Questions: What areas/indicators are essential for managing ART programs for the Region? Coffee available at 10 am	Groups. *Working group exercise number 2.*	Facilitator
12:30-13:30	Lunch		
13:30-14:30	Reporting to Plenary. Discussion and consensus	Group presentations: 10' each	Facilitator
14:30-15:00	Management and control of STI: What surveillance information do we need	Global STI control strategy and STI surveillance WHO recommendations. 20'	Richard Steen (WHO- STI Expert)

Agenda

	and how are we obtaining it?	Questions and discussion 10'	
15:00-16:00	Prioritize essential STI, identify gaps in current surveillance systems and propose plans for improvement. Coffee available at 15:00	Break out groups Sub regional groups *Working group exercise number 3.*	Facilitator
16:15-17:15	Reporting to plenary and main conclusions	10' each group	Facilitator
17:15-18:15	Poster exhibit on key populations.	Countries bring posters on: How they obtain and use information on MARPS and key populations. 1 hour market place.	Facilitator

Day 3. Friday November 9th, 2012

Rapporteur (morning only): Giovanni Ravasi, Karen Hymbaugh, Marjolein Jacobs
Facilitators: Marc Connolly (morning) Mónica Alonso González (afternoon)

Time	Subject	Format/Description	Responsible
8:15	Welcome to 3rd day.	Presentation of 1st session	Facilitator
8:30-10:00	Linkages among information systems: • Example of coordination between information systems: mother and child. • Example of coordination between information systems: Tuberculosis	Global monitoring framework for elimination initiative. UNICEF Maternal and child health data and HIV and Syphilis. Brazil WHO recommendations for HIV-TB monitoring. Country example TB-HIV from EL Salvador Chair with key messages and consensus	Chair: Priscilla Idele (UNICEF) Global monitoring framework for the HIV elimination initiative (Priscilla Idele, UNICEF) 15' Gerson Fernando(MOH Brazil) 15' Rafael Lopez Olarte (PAHO) 6' Dr. Sorto (El Salvador) 15' Plenary discussion and main themes 10'
10:00-10:15	Coffee break		
10:15-11:15	Strategic information for investment sustainability	Overview of investment framework Strategic information requirements for investment analysis (tools NASA, MoT and RNM) 15' Example of IF application in LAC 15' Discussion 20'	UNAIDS RST-LA UNAIDS RST-Caribbean

Agenda

11:15-13:45	Surveillance and monitoring among Key populations Questions: What populations are essential? What data are needed? How to obtain that information from the existing information systems? What are the advantages and disadvantages of special studies? How to promote translation of information to decision making?	Regional status on methods to do surveillance among key populations. 10-15' Table working groups with questions. *Working group exercise number 4*	Txema García Calleja (WHO) Facilitator Plenary discussion and closing
13:45-14:45	Lunch		
14:45-16:30	Recommendations and proposals that stem from the meeting; Presentation of draft recommendations. *Coffee available at 15:00*	Plenary with facilitator and draft to be discussed on screen	Facilitator
16:30-17:00	Conclusions and closing		

Working group results

The Regional consultation included several break-out sessions for group work. The working groups were organized as follows:

Group 1: Argentina, Bolivia, Costa Rica, Ecuador, Guatemala, PAHO, USAID, UNAIDS.

Group 2: Colombia, Cuba, Mexico, Panama, Peru, Uruguay, PAHO, CDC, UNFPA.

Group 3: Brazil, Dominican Republic, El Salvador, Honduras, Paraguay, Venezuela, CDC, COMISCA, UNAIDS, Health Focus, PAHO, Andean Health Agency

Group 4: Bahamas, Belize, Dominica, Guyana, Haiti, Jamaica, Suriname, Trinidad and Tobago, Jamaica, CDC, Public Health Agency of Canada.

Annex 1. Working group on HIV case-based surveillance

Discussion topic one: Do you agree that there should be a single regional definition of an HIV case for reporting and analysis? What minimum variables should be part of an HIV case reporting system?

Group 1

All countries have HIV reporting. An HIV case is one that has been confirmed as HIV-positive through country specific methods. There should be a regional definition for comparison purposes. The analysis is done based on individuals reported.

The minimum essential variables are:

- Institution name
- Unique identifier: to ensure non duplication
- Biological sex
- Gender
- Place of residence
- Age
- Date of Birth
- Diagnosis date
  Means of exposure: vertical transmission, sexual relations with a woman, sexual relations with a man, sexual relations with Trans, shared use of injected drug devices, blood transfusion, and work-related accident
- Education level
  Occupation
- Ethnic group (how do you self-identify?)
- CD4
- Clinical stage
- Marital status (optional)

Group 2

There is agreement on having a single regional definition of an HIV case for reporting and analysis.

The minimum variables for HIV case reporting are:

Unique ID
Name
Date of birth
Sex
Age
Local residence, municipality, state, ethnic group
Schooling

Reporting medical unit
Mode of transmission: homosexual
heterosexual, bisexual
Perinatal and Blood: IDU
occupational, post-transfusion)
For women: whether she is pregnant
Reporting date
Diagnostic confirmation date
Opportunistic diseases

Group 3

All the participants agree to a single regional case definition for HIV. The methodologies for a confirmed HIV case will be determined according to each country's algorithm.
Minimum variables:
Demographic: age, sex, pregnancy, date of birth, name and identifier code, origin (residence and reporting), diagnosis date, reporting date, ethnic group
Exposure category: commercial sex, did not use a condom, IDU, sexual abuse, occupational exposure
Sexual identity: trans, gay, MSM
Laboratory: CD4 and viral load
Date of initiation of ART
Date of death

Group 4

Yes
- Unique identifier - First 2 initials of first and last name
- Socio demographic data
  - Nationality
  - Age
  - Gender
  - Ethnicity
- Behavioural risk factors
  - sexual orientation??
- CD4 count at diagnosis and all CD4
- Viral load at diagnosis and all viral load
- ART
- Date of death
- Cause of death

Barriers
- Migration
- Non nationals will not have birth registration #
- AIDS/AIDS related complication is frequently absent from death certificate
- Absence of SOPs

Notes
- Active surveillance is necessary
- Case definition needs to be built into the system
- Importance of SOPs

Suriname has a UI (1st 2 initials from first and last name, DOB). No evaluation done re duplication. Challenges – instructions not followed by provider.
Is this a UI or is it a coding system to replace a name? Response- It serves both purposes. The physician usually asks for an ID card at testing.
What socio demographic variables would be pertinent?
Bahamas: nationality. The UI used is only in the STI clinic. Everyone at birth gets a birth registration number. Providers link each patient to this. For persons not born in the Bahamas this is challenging.
A lot of outreach in hot spots. Free HIV testing is done along with free credit. An anonymous questionnaire is

Annex

completed which includes sexual orientation and DOB.
Sexual orientation – this information was removed from the HIV testing form in Suriname
Barbados: Include risk factor on the VCT form. Once a relationship is built with the patient (during care and treatment) then the behavioural questions are included.
Jamaica includes questions that capture behavioural data on the VCT form.
Trinidad: Data captured for positive and negative clients alike through HIV testing intake form. Risk factors identified by CAREC is factored on the form.

Discussion topic two: What modifications do you need to make to have a functional HIVCBS?

Group 1
The countries have information systems, but HIV case reporting is delayed, lacking, or not proactive.
There is a need for integrated databases and improved information flow and quality. Processes and procedures should be institutionalized. It should be incorporated into each country's information system.

Group 2
Integration of surveillance, services, and laboratory information systems
Unique identifiers for cases
Functional information flows
Ongoing training

Group 3
The variables for several data sources can be interconnected to construct HIV data
Strengthen the data quality monitoring system
Develop the system's minimum assessment standards
Strengthen strategies for data dissemination and analysis, and feedback
Establish mandatory minimum variables for HIV case reporting
Epidemiology staff training in analysis of HIV information

Group 4
- Implementation of a system that is linked and comprehensive
- Include questions that capture behavioural data: working with NGOs to collect behavioural risk data – more likely to capture data from at risk groups
- Multi purpose health facilities in order to link services provided to the same client for CBS
- Public – private sector partnership
- Legislation
- Availability of data in the public domain eg on MOH websites

Barriers
- UI assigned based on services
- In Haiti no death certificate is required for burial
- Lack of relevant legislation

Discussion topic three: Is data collection on HIV cases in children and evaluation of PMTCT programs using an HIV case reporting system feasible in your country? What would be the barriers to this?

Group 1
Yes, it is feasible but there are many barriers, especially as far as monitoring, weak PHC, fragmented services, timely diagnosis, and record-keeping by the various actors.

Group 2
It is feasible to compile data on HIV in children.
It is difficult to evaluate PMTCT programs.
Barriers:
Lack of information in surveillance systems
Lack of monitoring of pregnant women for detection of critical links

Early detection of HIV in pregnancy Timely treatment, adherence Type of delivery (vaginal birth or caesarean section) NB prophylaxis and management NB monitoring to confirm or rule out the illness.
Group 3 It is feasible to compile information on HIV in children. **Barriers:** Loss of exposed children Under-reporting of cases of exposed children **Recommendations:** Raise awareness among maternal-child health workers Connect databases Ensure availability and improved costs
Group 4 Yes with challenges • Unique identifier needed • Definition of children/youth • Mother and baby each get registration number and both are linked – Bahamas • Data need to be common to both mother and child **Barriers** • Countries are not prepared for the transition from child to young adult • Gaps in data • Loss to follow-up • Paper-based systems – difficult to link • Name change with babies • Adherence

Discussion topic four: What do you think about including viral load and CD4 data as key improvements to HIV case based reporting in the countries and consequently in the region? Is monitoring of viral load and CD4 feasible in your country? If not, what solutions would you suggest?

Group 1 It is important, but only if it does not delay the information. It is feasible, but the problem is the timeliness of the data, which means data integration is important. There is a limitation, namely shortages of CD4 and VL reagents.
Group 2 It is necessary to have the results of CD4 and VL, but including it would lead to delays in case reporting. These variables could be included in case monitoring and the date of the initial count recorded in the systems.
Group 3 Agrees to including CD4 and viral load figures Seek new technologies that are more accessible to people Is it feasible? Yes. It should be done to monitor the quality of access to the health system. It should be discussed at greater length in order to keep it flexible so that it can be modified as it evolves.
Group 4 Yes. • Individual and programmatic perspective

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- Helps with the direction of the programme
- Informs testing programme

Is it feasible?

Yes

Added value:

- Adherence
- Indicator for late or early presenters
- Indicator for proportion of the population with AIDS
- Informs programming
- Compare countries and regions

Barriers

- Testing, reporting and follow–up done outside of country in many cases
- Migration
- Cultural including use of traditional medicine
- Referral and counter referral system

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Discussion topic five: Do you think it is important or pertinent to continue AIDS case reporting too?

Group 1
Is important to report advanced HIV infections
Group 2
Yes, it is necessary to continue with AIDS statistics It allows one to follow AIDS trends It facilitates evaluation of the effectiveness of ART in delaying the AIDS stage.
Group 3
Group 4
AIDS reporting as a continuum to HIV reporting. There is the need for an AIDS registry **Added value:** • Effective way of tracking treatment programme • Indicator for late presenting • Gives an idea of stage in relation to exposure and/or diagnosis **Barriers** • Duplication • CD4 change (backwards) – is the person still classified as having AIDS • AIDS cases not captured as HIV in some instances (Diagnosis vs staging). The two are sometimes added • Newly diagnosed case sometimes confused with a new infection

Annex 2. Working group on HIV care and treatment in the continuum of care

Overall comments from the groups

Group 1: Agree with the framework but still many indicators. It is important that countries conduct a feasibility analysis and cost for the reporting of these indicators. The barriers are closely linked to the effectiveness of information flow, and the real possibility of periodically conducting studies (eg, infrastructure, personnel, funding) and the availability of supplies and reagents in the health system. To help resolve this, it would be important: a. Ensure the involvement and commitment of the highest authorities; b. Ensure use of the information; c. Institutionalize processes and procedures of the HIV information systems, and standardize; d. And that population indicators fit the times in which national surveys are conducted in countries (biennial - every five years)
Group 2: We express agreement with this framework without this resulting in excesive burden for countries, but more as an opportunity for discussion on how to implement it and who would lead the process within the ministries of public health. In USA, surveillance was working in isolation and this permitted greater liaison with other instances and dialogue and joint work. Confidentiality was a transverse axis for all actors beyond own AIDS program, also means more alignment with the distribution of funds with the geography of the epidemic. In the region, this would mean alignment of surveillance with a dynamic monitoring to seek more sources and better quality of information produced.
Group 3: Framework make sense and many are indicators are already reported. The difficulties of countries to report indicators of the cascade must be considered. Need to develop indicator sheets or harmonize with them.
Group 4: On the cascade presentation: we suggest that an additional indicator at the end should capture HIV/ AIDS related mortality after VL suppression indicator. i.e: # of AIDS related deaths Dx linked to care Retention in care Indicators linked to care Capitalize on indicators already utilized for reports instead of increasing the number. Suggest harmonization of indicators and country prioritization on reporting.

A summary of the country review on the specific proposed indicators appears in Box 1. Overall of the 35 indicators there was full agreement on 22 as high priority key indicators for management of care and treatment programs. The need to more broadly disseminate these indicators (with their technical description sheet), clearly analyzing the purpose of each one is suggested in order to further disseminate the framework and how it supports program management.

Annex

Box 1. Summary of analysis on HIV diagnoses and treatment cascade indicator

Thematic Areas	HIV testing	Linkage to care	ART care	Adherence and Retention	Viral Load suppression
Key Cascade indicators	# and % of PLHIV who know their status, i.e. have been diagnosed with HIV infection,(Denominator: Tot estimated # PLHIV) (TasP Metrics Framework) and by MSM, SW and IDU.	# and % of newly diagnosed HIV cases who have been enrolled in HIV care and treatment services (TasP Metrics Framework) (proposed is numerator proxy	# of PLWH currently on ART: % out of total estimated PLHIV, and % out of PLWH elegible for treatment, (GARP and TasP Metrics Framework)	% of PLHIV that continue in care in last year (proxy: with 2 or more visits in last 12 months, altenative proxy variable with >=2 CD4/ year or 2 VL.year	% of total estimated PLHIV who are virologically suppressed (Denominator: Tot estimated # PLHIV) (TasP Framework)
Access/Coverage	# of newly diagnosed HIV cases in a given period.	Median time from HIV diagnosis to first CD4 count or VL.	# and % on ART by line of treatment (first, second, and third). (PAHO/WHO ART survey)	% of those initiated on ART who are retained in treatment after 12 months (GARP)	% of PLHIV on ART who are virologically suppressed (VL<400 copies), (Denominator: tot # on ART) (TasP metrics Framework)
	% of pregnant women who were tested for HIV and received their results (3.4 Universal Access)		Annual switching rate: % of PLHIV who switched regimens from first to second line due to failure (PAHO WHO ART survey) per	% of those initiated on ART who are retained in treatment after 24 months (Universal Access)	
	% of TB patients who had an HIV test result recorded in the TB register. (HIV-TB C1.1)		% of pregnant women with HIV who receive antiretrovirals to reduce the risk of mother-to-child transmission (GARP 3.1)	% of those initiated on ART who are retained in treatment after 36 months (TasP Metrics Framework)	
	% of SW, UDI, MSM who have been tested and know their status in the past 12 months (GARP 1.9, 1.13, 2.4)		% of estimated HIV-positive incident TB cases that received treatment for both TB and HIV (HIV-TB B1.2.2 GARP)	% of those initiated on ART who are retained in treatment after 60 months (Universal Access)	
	CD4 at diagnosis(baseline CD4 counts): median/% <350 / % <200			% of patients retained on first-line ART at 12 months (EWI 2010)	
	% persons with HIV positive results among those tested by subgroups (total, TB, pregnant women)				
	% of women & men 15-49 who received an HIV test in past 12 months and know their results (GARP 1.5)				
Quality	% of HIV positive pregnant women whose regular partner has been tested (mofidied TasP Metric Framework)	Percentage of adults and children newly enrolled in HIV care starting isoniazid preventive therapy (IPT) (HIV-TB B2.1)	# of ART regimens in use by 1st and 2nd line and # of patients in each regimen: % of patients on each regimen. % of patients taking obsolete ARV drugs (d4t,		% patients receiving ART after the first 12 months of ART whose viral load is <400 copies/ml (EWI 2011)
		% of adults and children enrolled in HIV care who had TB status assessed and recorded during their last visit (HIV-TB B2.1)	average # of viral load tests per patient on ART per year. Or % of persons on aRT with 2 VL per year		
		% PLWH enrolled in HIV care and eligible for co-trimoxazole (CTX) prophylaxis (according to national guidelines) currently receiving CTX	Mean cost per patient on ART.		
Others		% of DR detected among treatment-naive patients (HIVDR indicator) (surveillance sentinel surveys)	% of health facilities dispensing ARVs that experienced a stock-out of at least 1 required ARV in the last 12 months (Summary EWI		
			Número de quiebres de stocks en un período dado según la definición operacional (reunión DOR)		
			# of health-care workers employed in facilities providing care for PLWH who develop TB during the reporting period. (WHO HIV-TB B3.3)		

Notes: Color codes: Green= high priority; yellow= intermediate priority; red= low priority; There is a bubble call symbol in those cases when groups had differing opinions on priority. The color of the bubble reflects the assigned priority level by another group.

Annex

Detailed results from analysis of each indicator

Subject: HIV testing (contributing groups: 1 and 2)		
	Number and percentage of PLH that know their serological state, i.e. have been diagnosed with HIV (denominator: estimated total number of PLH) by group: MSM, SW, and IDU.	
	Observations	**Priority**
Group 1	The indicator is relevant, but the IDU population should be optional Clarify whether data collection on high risk groups will be done through a special study or based on Information system registries. Countries should have the flexibility to add other groups to the breakdown as they deem necessary.	High
Group 2	Most countries use Spectrum to estimate the denominator; limitations of the S system in registering reports; limitations on access to testing.	High
	Number of new HIV cases in the period.	
Group 1	This indicator is the basis for other indicators.	High
Group 2	All the countries have this data	High
	Percentage of pregnant women who were screened for HIV and received their results.	
Group 1	Determine whether the denominator is national projection of pregnant women or pregnant women programmed by the health system. (also makes a change to this indicator: replace "were screened" with "have been tested")	High
Group 2	It is contingent on access to the test and availability of information from the maternal health areas on prenatal checkups.	High
	Percentage of TB patients who were tested for HIV and whose results were registered.	
Group 1	No additional comments	High
Group 2	It is contingent on coordination with the TB program so that it is registered and reported and the algorithm of each country is followed.	High
	CD4 diagnosis (basal CD4 count): median/% <350 / % <200	
Group 1	It can take time for CD4 results to become available. If they are to be used, it would have to be an annual indicator and be useful for advocacy and campaigns on access to testing. (Also makes a change to the indicator: replace "CD4 diagnosis" with "CD4 count at diagnosis")	High
Group 2	If it is an indicator of early/late, timely access to diagnosis, it should be ascertained within 3 months of the initial diagnosis; having the CD4 count at diagnosis is an indicator of access to health care.	High
	Percentage of people screened who have received an HIV-positive result, by sub groups (total, TB, pregnant women)	
Group 1	Clarifies that it is an indicator of positivity; it cannot be a substitute for prevalence.	High
Group 2	No additional comments	High
	Percentage of women and men age 15-49 who received an HIV test in the past 12 months and know their results.	
Group 1	It is not that useful in concentrated epidemics.	Low
Group 2	The source of information is population surveys for people ages 15 to 49.	Low
	Percentage of SW, IDU, MSM that have received an HIV test in the past 12 months and know their results.	
Group 1	Some countries have difficulties obtaining this indicator The group did not reach consensus as to whether to designate this as green or yellow	High/intermediate
Group 2	It cannot be evaluated with routine studies. Specific population studies or surveys	Intermediate

	are required and usually few resources are available for this. In addition, not all groups have the same priority, depending on the country.	
	Percentage of HIV positive pregnant women whose regular partner has been screened.	
Group 1		High
Group 2	The programmatic elimination initiative includes active offer of testing to couples, regardless of their status, for early diagnosis, taking advantage of capture of women during pregnancy. It can be an indicator of access as well as quality of care. The feasibility of collection has a strong influence on priority level. Information capture and quality is also complicated.	Intermediate

	Subject: Linkage to care (contributing groups: 1 and 2)	
	Number and percentage of new HIV cases that were enrolled in HIV care and treatment services (initial CD4 count is proposed as a proxy numerator)	
	Observations	**Priority**
Group 1	No additional observations	High
Group 2	Numerator: person diagnosed with CD4; denominator: people diagnosed in a given time period. How many people seek care and when they seek it are indicators of linkage to care.	High
	Percentage of adults and children enrolled in HIV care that began preventive therapy with Isoniazid.	
Group 1	Makes a change to in the indicator: replace "enrolled in care" with "receiving care for"	High
Group 2	In favor of this indicator is the fact that coinfection and case-fatality is high in our region considering the health systems. But this indicator tends to be poorly reported and with low coverage. Usually a distinction is not made between HIV cases and TB cases in the registries. It would be important to establish that this data is collected.	Intermediate
	Percentage of adults and children enrolled in care for HIV for whom a TB test was recorded on their last visit.	
Group 1	Early detection of patients with TB among the PLH. (Makes a change to the indicator: replace "enrolled in care" with "receiving care")	High
Group 2	This indicator can only be obtained from the medical history; it is difficult to collect and few countries report it.	Low
	Median length of time between the HIV diagnosis and the first CD4 or Viral Load count.	
Group 1	It would be more useful to know the median time lapse between confirmation that the patient needs treatment and he or she actually receiving it	Low
Group 2	Since it is an indicator of quality	High
	Percentage of PLH enrolled in HIV treatment that are eligible to receive cotrimoxazole (CTX) prophylaxis (according to national technical standards) and are currently receiving CTX prophylaxis (broken down by age: under 2 years of age)	
Group 1	Makes a change to the indicator: "enrolled in care" by "participating in a treatment program"	Intermediate
Group 2	The denominator is difficult to calculate since not everyone is eligible, and then who receives the treatment.	Low
	Percentage of patients with ARV drug resistance in treatment naïve patients.	
Group 1	No additional comment	Intermediate
Group 2	It is based on sentinel surveillance; conduct special surveillance to evaluate how many newly diagnosed (and treatment naïve) patients present with transmitted resistance, based on subsamples in a certain period (all those diagnosed in the next 3 months). It offers clues for evaluating available first-line regimens. In our countries, resistance testing is recommended at the first biological failure. Keep in mind the benefits for treatment	High/Intermediate

Annex

	program management, which is the primary value of this type of measurement, beyond reporting at the global level.	

Subject: ART (contributing groups: 3 and 4)		
	Number of PLH currently in treatment: **Percentage relative to the total estimated PLH, and** **Percentage relative to the total PLH eligible for treatment.**	
	Observations	**Priority**
Group 3	Standardize the indicator in the monitoring description of indicator sheets	High
Group 4	Wording: replace estimated with eligible Disaggregate by MARPS eg MSM/SW/DU on ART Barrier: How do we collect it? % out of PHIV eligible for treatment: Yellow	High
	Number and percentage of people in ART by treatment line (first, second and third)	
Group 3		High
Group 4	Green: country specific. Yellow : as an aggregate regional indicator Barriers: No standardized regimens; no follow-up on adherence to treatment guidelines; practitioners using 2nd line as 1st line Solutions: Define, standardize, simplify 1st and 2nd line regimens. Involvement of the pharmacist and patient in of oversight of adherence to Rx protocol. Economic implications	High
	Percentage of pregnant women who are receiving ART to reduce the risk of mother-to-child transmission	
Group 3	Clarify the indicator sheet and determine which will be the standardized denominator	High
Group 4	Barriers: Only public sector data (65-90%)- incomplete national data Solutions: Compromise in regards to the level of reporting required, provide supplies and involve in treatment	High
	Percentage of health facilities that deliver ARV and have experienced a stock-out of at least one ARV drug in the past 12 months.	
Group 3	Disseminate the definition of stock out developed in the Dominican Republic Comply with the universal access guideline on indicators	High
Group 4	No additional comment	High
	Number of health workers who provide care for people living with HIV and developed TB during the reporting period.	
Group 3	Since it is a nosocomial surveillance indicator	Low
Group 4	No additional comment	Low
	# of ART regimens in use by 1st and 2nd line and # of patients in each regimen: % of patients on each regimen. **% of patients taking obsolete ARV drugs (d4t, IDV, nfv, ddi)**	
Group 3	No additional comment	High
Group 4	Not clear: How do we compare countries based on the # of regimens being used by individual countries? How do we report on substitution of a drug vs changing regimens? Procurement of drugs by/thru pharmaceutical bodies to control obsolete drug use	High
	Annual change ratio: Percentage of PLH whose treatment is changed from first to second line due to failure each year.	
Group 3	It is a percentage, not a ratio; proposes expressing it as a percentage.	High
Group 4	Barriers: Lack of standardized, adherence to protocol Define 1st & 2nd line regimens; is DR an issue for countries at this point in time??	High/Intermediate
	Estimated percentage of incident cases of HIV-positive people who have TB, who receive treatment for both TB and HIV.	
Group 3	The countries have made varying degrees of progress in data reporting. An evaluation of the TB/HIV joint plan is recommended. This is a priority indicator and collection is difficult WHO provides the denominator	High

Annex

Group 4	Complicated indicator. Most countries cannot report on this indicator as is because HIV and TB programs are not integrated; therefore recommend integration Percentage of incident TB cases tested for HIV Percentage of TB/HIV patients treated for both The relevance of this indicator is based on the burden of TB in the country	missing
	Average number of viral load tests per patient on ART per year. Or percentage of people in treatment with 2 viral load tests per year.	
Group 3	Due to lack of compliance with the protocol and/or shortage. Develop the indicator sheet that with a clear objective and purpose for the indicator	Intermediate
Group 4	Do we include VL tracking for those in care vs those on ART……preferably CD4 to minimize cost	High
	Average cost per patient on ART.	
Group 3	What do I want it for; the indicator sheet should be developed	Low
	Implies treatment or care	
Group 4	Do we include cost of managing a patient (tedious) vs cost of ART for patients 1st line ART Operational definition as to purpose of indicator	missing
	Number of stock-outs in a given period according to the operational definition (DOR meeting)	
Group 3	Disseminate the definition of **stockout** developed in the Dominican Republic Review the technical sheet for the indicator	High
Group 4		missing

Subject: Adherence and retention (contributing groups: 3 and 4)		
	Percentage of people who remain in treatment 12 months after initiating ART.	
	Observations	**Priority**
Group 3	None	High
Group 4	None	High
	Percentage of people who remain in treatment 24 months after initiating ART.	
Group 3	None	High
Group 4	None	High
	Percentage of people who remain in treatment 36 months after initiating ART.	
Group 3	None	High
Group 4	None	High
	Percentage of people who remain in treatment 60 months after initiating ART.	
Group 3	None	High
Group 4	None	High
	Number and percentage of PLH that currently receive care (proxy: with 2 or more visits in the past 12 months, alternative proxy variables with ≥ 2 CD4 tests /year or 2 VL tests/year, or medications pick up)	
Group 3	Denominator is the estimated number of people; CD4 is a good possibility as a proxy; define minimum care, develop the technical sheet	Intermediate
Group 4	Include VL tracking for those in care (or vs those on ART?)……preferably CD4 to minimize cost	High
	Percentage of patients retained in first-line treatment for 12 months.	
Group 3		High
Group 4	Adherence indicator- difficult to define e.g. % of patients that pick up ARVs at least once a month-based on appt/pharm system.	missing

Subject: Viral load suppression (contributing groups: 2, 3 and 4)	
	Percentage of PLH in treatment who are virologically suppressed (CV<400 copies)	

Annex

	Observations	Priority
Group 2	Both offer a more complete picture of the populational situation in the country.	High
Group 3	Make sure the indicator sheet is WELL-defined.	High
	Number and percentage of the total estimated PLH who are virologically suppressed.	
Group 2	This indicator provides information on all those who have a detectable viral load, are not aware of it and could transmit it. Therefore, it provides a percentage for the virus circulating in the country, risk of transmission, closing the cascade with the effect on the population. It can also be done, obviously, with those in treatment at a certain period in time, which elicits the quality and effectiveness of care. If I do it for most at risk groups, I can estimate transmission risk. It is not a matter of evaluating treatment effectiveness, but rather what is going on with the population, what may be occurring if they are behaving like the group about which I have information.	Intermediate/Low
Group 3	Make sure the indicator sheet is WELL-defined.	High
Group 4	Indicator seems too complicated	Low

Annex 3. Working group on surveillance of sexually transmitted infections

Please indicate the essential elements of STI surveillance and how feasible you think it is to have these elements functionally in place in your country?

Group 1 Essential elements: •   Congenital syphilis •   Case monitoring up to cure (in all subpopulations) •   There are variations in what countries are registering: some etiological data, others syndromic, others both.
Group 2 There is variation in the group with regard to STI surveillance systems, which complicates disaggregation of the type of syphilis. There are no problems reporting syphilis and congenital syphilis, except in one country. Half of the countries have data and mechanisms for gonorrhea surveillance.
Group 3 •   It is feasible, necessary, and useful •   We need to know the reason for the primary, secondary and latent report, since the programming response is the same. •   Include MARP data for prevalence monitoring
Group 4 •   Urethral discharge •   Genital ulcers •   Syphilis (Including Congenital) •   Gonorrhea •   Gender, age, stages •   Feasible to implement in the countries (being reported to CAREC) Recommendation: Chlamydia – more cases than GC but less feasible due to in-country diagnostic capacity and cost (country specific eg. Barbados, Bahamas – combined Chlamydia and GC) **Incident case reporting** •   Syndromic STI diagnosis (by age and syndrome) already being done in the Caribbean in collaboration with reporting to CAREC •   Aetiologic STI diagnosis (Syphilis and Gonorrhea and age) - as above •   Congenital Syphilis – challenges with reporting -   lack of registries -   lack of case definitions for congenital syphilis -   Lack of linkages of treatment for syphilis positive pregnant woman and follow up with newborn. **Routine prevalence monitoring** 1. Antenatal syphilis screening – reporting is being done but there are challenges •   Challenge -   No specific reporting systems 2. Sex worker syphilis screening – very challenging as there are no specific programmes nor treatment facilities for SW (SW illegal in the Caribbean) •   Haiti and DR have special facilities for SW making it easier for reporting

Please, identify 3 key gaps in the current STI surveillance system in your country

Group 1 Laboratories lack supplies for etiological diagnosis Underreporting due to: o   In particular, people who go directly to private pharmacies (especially males) or to the first level of

care (MARP)
      o   Health workers do not maintain up-to-date records
      o   Has the practice of contacting sexual partners to rule out and treat STI been lost?

Group 2 1.   Quality of the diagnosis 2.   Not all entities are included in the surveillance systems 3.   Lack of surveillance protocols and criteria
Group 3 •   Availability of laboratory supplies to report etiological diagnoses •   Little availability of treponemal rapid tests •   Staff training for etiological diagnosis, treatment and reporting
Group 4 •   Challenges with private sector reporting in some countries •   Limited collaboration (public/private) Haiti: reporting is driven by external funding •   Over the counter medication given by pharmacists – not reported If this is consistent then the incomplete data can be analysed •   Absence of surveillance systems for STIs

Based on the key gaps previously identified, please propose 3 key elements that would improve the STI surveillance system

Group 1 Essential elements: •   Trained and sensitized human resources •   Supplies available •   Services for sex workers •   All the laboratories in the country should perform etiological STI diagnoses
Group 2 •   Establish a basic guide for implementing STI surveillance in the region •   Boost diagnostic capability in countries •   Identify useful information available in other services.
Group 3 Did not have enough time.
Group 4 •   Provide incentives for private sector reporting (Jamaica: MOU signed between Govt and a few private practitioners) •   Forge public/private partnerships eg with other diseases (immunization programme) •   Enforcing legislation for reporting (last resort – not a big stick policy) •   Legislation for dispensation of medication by pharmacists •   Implement surveillance systems for STIs

Annex 4. Working group on surveillance in key populations

What information on key populations/MARP can be obtained from routine information systems? What systems? How are key populations identified through these systems?

Group 1
Routine information systems: In some countries through the case reporting sheet.

Group 2
For routine surveillance the countries: use the same formats, some ask about identities or population groups and others about behavior, some both variables. However, there are reservations about the quality of information collected: it is partial, heterogeneous, and limited, depending on the individual who is collecting the information. For this reason, the information on MARP that can be collected through case surveillance is too limited to be useful for public policy.

Group 3
What information on populations from routine systems?: number of cases, distribution by sex, transmission category, age, residence What systems?: case reporting sheet How are key populations identified through these systems?: gender identity and risk behavior variables

Group 4

• Routine information systems: Case based surveillance/Routine surveys every 2-3 yrs-Haiti, Guyana, Suriname, DR
• Data generated by these systems :   ---
    1. HIV/STIseroprevalence-varies with countries,
    2. Risk behaviour factors and KAP information
    3. Sociodemographic information, size estimates (same as above),
    4. Spending data (NASA/MEGAS)
How are these populations identified in these systems?
Formal/Routine
Informal/adhoc
Case based surveillance variables for risk behavior- are they reliable? (this question is pertinent because they come self-reporting), referral from MARPS service sites, community based formal referral and counter referral system (exists in Antigua, DR, Trinidad, Dominica), involvement and support from the Gender Affairs Ministry (Antigua), Sex workers Association (Jamaica)

What other information is made available from special studies or sentinel surveillance? What problems do these studies pose? Or, what problems have been encountered with sentinel surveillance?

Group 1

Special studies or through sentinel surveillance:
    • Behavioral studies
    • Prevalence
    • Coinfections
    • Resistance
    • Access to health services and resources
Problems:
    • Financing
    • Planning
    • Technical resources to develop studies
    • Population representativeness
    • Integration of research agendas

• Access to key populations
Group 2 Information on types of prevention, behavior (condom use) can be obtained, as well as HIV and STI prevalence. Knowledge, behaviors, education level, economic factors, and access and use of health systems. Problems posed by such studies: the challenge of availability of resources to carry them out. Using resources from outside the country for this complicates long-term planning, with objectives of assessing trends. It is difficult to take on the alternative of channeling resources toward research when there are needs in terms of care and treatment for HIV-positive people. In general, Global Fund projects do not leave the ministries with their own local installed capacity. In Mexico, however, routine access to testing for 100% of pregnant women was installed. Second-generation studies per se are not going to solve the information problem. They are necessary, but routine surveillance systems must be strengthened. With the Treatment 2.0 approach, to the extent that earlier diagnosis is achieved through expanded supply of diagnosis in order to facilitate access to treatment, we will move closer to incidence. It would be useful if we had a surveillance plan tailored to the needs, rather than act only when funds are available.
Group 3 What other alternative information is made available from special studies or sentinel surveillance?: prevalence and behavior; further detail on social determinants; STI; opportunistic infections and comorbidities; incidence and resistance, populations deprived of their liberty. • What problems have been encountered with sentinel surveillance? • Tendency to overload studies • High costs (mainly from international cooperation). • Need for local personnel trained in design and information analysis, need for professional academic formation. • Additional research functions for health workers on the programmatic areas in which they are working. • Migration toward other types of methodologies. • Lack of dissemination of the results among the general public.
Group 4 *What other alternative information is made available from survey or sentinel studies?* • Mode of transmission • Data to validate routine data collected: application of qualitative research techniques • Quality • Specificity of other key population • Needs assessment/rapid assessment (quality:programmatic/expenditure) • Effectiveness of social protection programs • Level of/perception of S&D • Access to services • Channeling M&E info on key population derived from NGOs into international surveillance systems *Issues of studies* • Validity, • scientific rigourosity- methodology • Representativity- access to networks ? • lack of dissemination plan • Lack of plans for triangulation • Biases in Sample selection- • HR selection to capture data-studies (gatekeepers in key pop) • Costly, lack of and capacity of HR, time consuming

How is the information on key populations used? And what can be done to improve it? (For example, is it used at the subnational level...?)

Annex

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Group 1
- To guide policy in different areas
- Fundraising
- Political advocacy
- To inform modeling, estimates, measure targets, country commitments
- Feedback at the subregional level

Actions to improve the use of the information
- Improve information sharing
- Think strategically about dissemination
- Boost capacity to define agendas and channel resources
- Work with agencies that drive research agendas and funding at the country level.
- Guarantee human resources

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Group 2

This information was useful in drafting and justifying the proposal for the Global Fund's 10th round; channeling resources from the national strategic plan towards the most vulnerable groups; drawing on epidemiological information to raise the awareness of agencies and institutions about stigma and discrimination through a geo-referenced depiction containing mortality data and prevalence among these groups. Also for national strategic plans and resource allocation.

The proposal for improvement is that the authorities recognize the need to conduct studies and allocate funds to do so.

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Group 3

How is the information on key populations used?
- To secure political support, fundraising, and reorganization of services based on behavioral studies.
- Spotlight at-risk populations, targeted prevention campaigns.

What can be done to improve it?
- Disseminate the wealth of information to expand government prevention services targeted towards MARP.

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Group 4
- answer indicators- national/international
- Appropriation of funds
- Should be used for national response and strategic planning
- Advocacy-program interventions
- Educate the populations at risk
- Evidence-based programming
- Resource mobilization-targeted interventions

How can we improve data use?
- Providing funding for advocacy independent of service provision
- Advocacy for policy change

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</table>

Annex

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