

## Technical Assistance Brief

# Epidemiological Surveillance

## Leveraging Data to Monitor and Respond to Epidemics

### Epidemiologic Surveillance

Epidemiologic surveillance is the measure and monitoring of a disease in a population that allows public health professionals to understand the rate, trend, progression, and impact of the disease, and the need for and outcomes of public health programs. These data are of use to plan for, monitor, and guide impactful public health programs.

Epidemiologic surveillance of HIV, TB and STIs has been in practice for decades, and has allowed countries and funders to focus resources where needs are noted.

The World Health Organization (WHO) and UNAIDS updated and re-released guidance on second generation surveillance in 2013 to describe five components of an integrated surveillance system.<sup>1</sup> They include:

- **HIV/AIDS case and mortality reporting**
- **STI surveillance, often from sentinel sites**
- **Antenatal Clinic sentinel surveys (ANC)**
- **Integrated Biological and Behavioral Surveillance surveys (IBBS)**
- **Size Estimation of higher-risk groups.**

Together, these data help to develop a profile of an epidemic.

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<sup>1</sup>[http://apps.who.int/iris/bitstream/10665/85511/1/9789241505826\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/85511/1/9789241505826_eng.pdf)

### NASTAD Building Capacity for Epidemiologic Surveillance

For more than 10 years, the National Alliance of State and Territorial AIDS Directors' (NASTAD) Global Program has partnered with host country governments to build their national capacity to implement and use second generation epidemiologic surveillance methods and the resulting data in order to plan for, implement, and monitor and evaluate evidence-based public health programs. To support local and sustained capacity building, NASTAD uses three methods:

#### - Knowledge Transfer for Sustainability

While NASTAD can support development and implementation, all work is planned and put into action in collaboration with the local government. NASTAD partners with local expertise, and provides side-by-side applied technical assistance and mentoring, to support country-owned and managed systems.

#### - Training & Operational Support for Local Design and Ownership

To support implementation success, NASTAD provides formal and informal needs-based training in areas such as system design, staff leadership and management, process M&E, and data analysis, presentation and use.

#### - Product Development

NASTAD also contributes to the development of tools and templates to document processes and facilitate success, such as protocols, Standard Operating Procedures, databases, and reports.

## NASTAD

The National Alliance of State and Territorial AIDS Directors (NASTAD) represents the United States' chief state and territorial health directors with programmatic responsibility for HIV/AIDS, viral hepatitis, and associated public health programs. NASTAD's Global Program works to build the organizational and human resource capacity of its HIV/AIDS program counterparts across the world. The Global Program uses a peer-to-peer capacity building framework to enhance local leadership to gather and use data to plan, manage, and evaluate HIV programs.

### **NASTAD: Integrated Biological and Behavioral Surveillance surveys**

NASTAD has worked with four countries to plan for and/or implement Integrated Biological and Behavioral Surveillance surveys (IBBS) and population size estimation focusing on youth, men who have sex with men (MSM), and female sex workers (FSW).

In line with NASTAD's capacity building model, NASTAD identifies international expertise to support county-specific growth, and works over time to ensure that national public health agencies have the ability to plan for and implement IBBS surveys independently.

NASTAD's technical expertise in this area comes from its years of experience supporting U.S. states to implement Youth Risk Behavior Surveillance system<sup>2</sup> (YRBS) and the National HIV Behavioral Surveillance survey<sup>3</sup> (NHBS). Using members as short-term technical assistance providers, NASTAD has been able to partner with ministries of health and national epidemiologists to:

- Define the surveillance needs and epidemiologic questions
- Identify existing and proven methodology
- Modify and adapt the methodology to meet local needs
- Develop locally-focused survey tools
- Develop staffing and training methods that build from existing structures and resources
- Provide training, supervision and mentorship to facilitate successful implementation
- Assist with database management, data quality assurance, and data analysis
- Present survey findings and engage stakeholders in evidence-based planning.

NASTAD has a variety of resources that may be of interest and can be adapted to countries:

- YRBS, MSM IBBS, and FSW IBBS protocols, surveys and standard operation procedures.
- IBBS planning and implementation ToolKit.

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<sup>2</sup> <http://www.cdc.gov/HealthyYouth/yrbs/index.htm>

<sup>3</sup> <http://www.cdc.gov/hiv/bcsb/nhbs/>

### **NASTAD: Antenatal Clinic survey & PMTCT Data Utility Evaluation**

NASTAD has worked with one country to assist them to take the lead in implementing an Antenatal Clinic sentinel survey (ANC), and to concurrently implement an evaluation in line with the World Health Organization's Guidelines for Assessing the Utility of Data from Prevention of Mother-to-Child Transmission (PMTCT) Programmes for HIV Sentinel Surveillance Among Pregnant Women.<sup>4</sup> This partnership resulted in two strong outcomes:

- With NASTAD's support, the local government took on a greater role than ever, implementing the ANC survey, and as such, was able to improve the technical capacity of staff related to quality control, human resources management, program and process monitoring and evaluation, logistics coordination, and data analysis.
- Review of the routine program data from PMTCT facilities that participated in the ANC survey showed the data quality to be sufficient such that register data could be used as a measure of HIV prevalence among pregnant women. The resulting recommendations are that the country:
  - Redoubles M&E and quality management (QM) efforts in PMTCT sites to ensure consistent use of national tools, in line with national guidance, and
  - Uses routine PMTCT program data to assess HIV trends among pregnant women in place of costly, point-in-time ANC surveys.

These recommendations are significant in that they will drive resources to be invested in M&E and QM, which can support widespread impact, and allow for national monitoring of HIV trends among pregnant women on a routine and ongoing basis rather than biennially from sentinel sites.

NASTAD is now supporting implementation of these recommendations.

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<sup>4</sup> <http://www.ncbi.nlm.nih.gov/books/NBK159001/>

## NASTAD: Leveraging Routine Program Data for Epidemiologic Profiling and Public Health Action

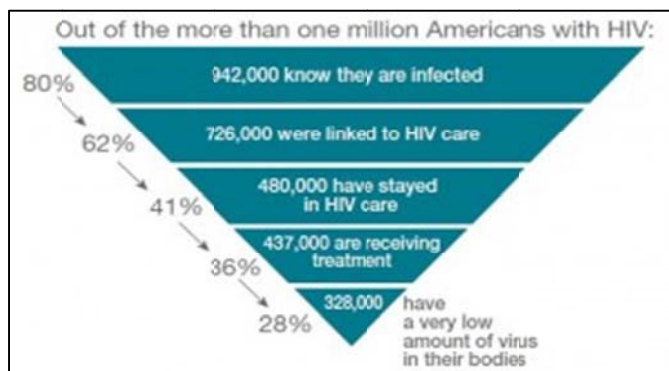
Health systems in developing countries, including strategic information systems, have expanded greatly in order to provide and monitor HIV and related health programs. This growth has resulted in vast amounts of data being collected at the point of service; however, few methods are currently used to leverage the data for public health improvement.

Based on U.S. experience, NASTAD is committed to evidence based programming, and as such, supports initiatives to better use available data. As an example, many countries report gaps in disease-specific strategic information for epidemiologic profiling and program planning, such as:

- Demonstrating linkage to care post-diagnosis (Figure 1)
- Documenting clinical outcomes and needs via the “treatment cascade” (Figure 1)
- Quantifying true loss-to-follow-up
- Documenting perinatal exposure, outcomes and needs
- Quantifying patient mobility and/or pan-system duplication
- Quantify factors that are contributing to disease transmission.

NASTAD has shown that these information gaps can be addressed via the collation and analysis of existing person-level data; this is consistent with UNAIDS guidance on the use of HIV/AIDS case and mortality reporting.

*Figure 1: Sample Clinical Cascade, U.S. CDC<sup>5</sup>*



<sup>5</sup> <http://blog.aids.gov/2012/07/hivaids-treatment-cascade-helps-identify-gaps-in-care-retention.html>

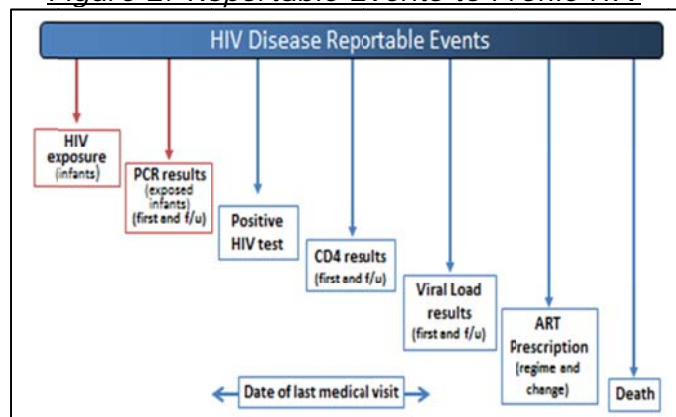
## Case Reporting & Case-based Surveillance

Case-based surveillance provides a specific and representative picture of an epidemic at any point. The method is based on three criteria:

- Reporting of all known cases of a disease;
- Reporting of defined clinical events that demonstrate disease progression (e.g., HIV: Figure 2); and
- Linking case reports related to one person to demonstrate each case's 'history'.

When all case histories are combined, a picture of the epidemic, program outcomes, and service needs/gaps is identified.

*Figure 2: Reportable Events to Profile HIV*



While these criteria may seem daunting, NASTAD has demonstrated that the data and mechanisms to support case reporting may already be available in countries that routinely collect program data. The barrier to using the data is often only collating and linking cases in a central location.

Solutions that NASTAD has worked with countries to develop include:

- Case reporting pathways that use existing paper or electronic data flow processes
- Expansion of patient-level data collection, such as risk factors for HIV transmission, to support epidemiological profiling
- Development of pseudo-unique identifiers to allow for case report matching, case tracking, and outcome evaluation
- Development of locally-managed databases that automate case reporting and analysis from existing but not-linked data systems, such as electronic medical records.

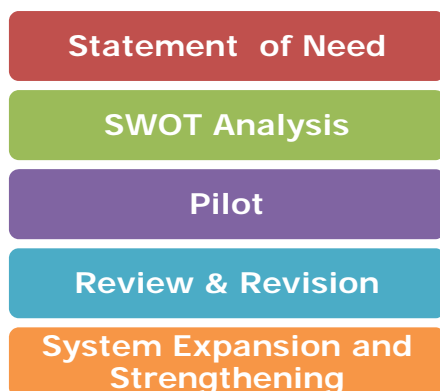
## NASTAD: Case-based Surveillance

NASTAD is working with five countries to evaluate and support better use of their existing program data and data management systems to allow for case-based surveillance of HIV and AIDS and related co-infections.

NASTAD's approach to this area of work leverages U.S.-based experience, and builds on successes and lessons learned. NASTAD believes that systems must be simple, accessible, locally managed, and usable.

As depicted in Figure 3, NASTAD provides technical assistance to partner governments in an iterative process, and builds from and uses existing systems and resources.

*Figure 3: Surveillance System Development Process*



### Statement of Need

Before initiating any capacity building activity, NASTAD meets with the host government and funder to understand and define project goals. Because the development of any strategic information system will require fiscal, human, and time resources, a clear statement of need must be developed.

### SWOT Analysis

In order to assess the feasibility of meeting the proposed project goals, in line with the statement of need, NASTAD works with the host government to implement an environmental scan. In this process, NASTAD supports a review of existing resources (systems, human, data), motivation, stakeholder support, as well as potential barriers and limitations. This hands-on approach allows for evidence-based planning of the next steps, if indicated.

### Pilot

Based on the findings of the SWOT, NASTAD works with the host government to design demonstration projects to test the feasibility of the proposed project. Examples of this include:

- Development of simple and expandable local databases to manage case reports and to allow for case-linking and disease progression analysis.
- Data interoperability exercises to leverage and merge existing person-level data from multiple non-networked electronic systems.
- Use of pseudo-unique identifiers (codes generated from patient demographics) to link cases where true unique patient identifiers do not exist.
- Real-time use of networked and linked data to improve linkages and reduce loss-to-follow-up via a counter referral process and/or 'patient-look-up' system.

### Review and Revision

NASTAD uses a pilot methodology that is consistent with the Plan-Do-Study-Act model for quality improvement so that resources are not wasted and that positive findings are built upon. In that way, pilot or proposed system review and expansion happens on an ongoing basis, so that the project grows as the system and evidence supports.

### System Expansion and Strengthening

In the countries where NASTAD is providing support case-based surveillance, system expansion to the national level has happened at different rates, dependent on the host government's direction. As the government prepares for scale-up, NASTAD supports system strengthening in the form of:

- Capacity building, mentoring, and/or fiscal support of high-level technical staff and system managers;
- Training development and supported roll-out to ensure health worker capacity;
- Process and data monitoring and evaluation system development; and
- Supported data analysis and dissemination for evidence-based decision making.

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