Epidemiological Surveillance

Epidemiological surveillance is the practice of measuring the incidence of a disease in a population, monitoring the progression of disease and/or the clinical outcomes, and providing strong public health data to guide impactful programs.

Epidemiological surveillance of the HIV epidemic has been in practice for decades, most frequently relying on population estimates drawn from population-based surveys such as Antenatal Clinic Surveys and Demographic and Health Surveys. While these data are representative of the populations surveyed, and may be extracted in relevant fashion to the general population, neither are precise and specific to the general population, and both are costly—in dollars and human resources—to implement on a regular basis.

With the proliferation of HIV services, and the data collection and program monitoring and evaluation systems that accompany them, a more routine method of epidemiological surveillance, case-based surveillance, is being proposed around the world.

Case-based Surveillance of HIV

Case-based surveillance is the practice of measuring and monitoring the incidence, progression and outcome of a disease via the collection of patient-level data for a series of key or sentinel (reportable) events. To be successful in this process, there must be a way to:

- Capture patient-level data across the spectrum of disease, including, for example, HIV diagnosis, AIDS diagnosis and death
- Identify each specific case (person) at the central (data management) level
- Link multiple reports on one case (person) to each other.

To implement this method of surveillance, five elements are required.

- **Definition of Sentinel Events**

  In order to implement case-based surveillance, the data you wish to collect, manage, monitor, and respond to must be defined. In order to capture useful disease progression data while not overburdening staff, the following sentinel events are suggested as reportable:

  - **Core HIV/AIDS Surveillance**

    Reporting the Spectrum of HIV/AIDS Morbidity and Mortality

    - **Entry into Care**
      - Date of Entry (date)
    - **Infectious (CD4)**
      - CD4 < 200 (value)
      - CD4 > 200 (value)
    - **Clinical Diagnoses**
      - WHO Stage 3 & 4 AIDS (value)
    - **Death**
      - Date of Death (date)

  In addition to reporting the event that is observed, the date of observation and other associated values, the collection of basic demographic data will be invaluable to the data analysis and related program planning process. Demographic data that should be considered include:

  - A patient identifier
  - Date of birth
  - Gender
  - Geographic location (of birth, of residence)
  - Likely mode of HIV transmission
  - Other related transmission/risk factors
  - Other pertinent information for program planners.
- Method to Report Events
To receive data at a central location, the process of data reporting must be clearly defined. Typically, a case report form is used to collect initial patient-level data at the point of diagnosis, and again as a patient moves through a sentinel event. Frequently, the case report form can be completed using data already collected in patient registers or medical records; case report forms are submitted to a central location for data management. This process can be paper-based, or, where electronic patient-level data management systems exist, these can be leveraged to produce and provide data in an automated fashion.

- System to Manage Reported Data
At a central level, a system must be available to manage submitted patient-level data. This means staff for data entry, cleaning, management and report generation, and the existence of a simple database. If data are to be reported and received electronically, perhaps from multiple sources, the database will need to be marginally more complex. A system such as EpiInfo or Access is reasonable.

- Process to Link Reports
As multiple reports are received per patient (as they are diagnosed and then progress through sentinel events) or if there is an assumption that a patient may be reported from one or more facilities, a process to link patient-specific reports to each other is required. Processes to consider include:
  - Use of patient name for each case report,
  - Use of a national unique identifier for each report, or
  - Use of a proxy unique identifier such as fingerprints or iris scans.
As these options are considered, developers should be mindful of what types of identification are available at a national level, and what is the norm in accessing health services.

- Commitment to Respond and Use Data
Finally, a case-based reporting system should not be considered unless there is a commitment to routinely clean, link, analyze, and release (aggregate and un-identified) the data to allow for targeted and applied program development, improvement, and implementation.

NASTAD
The National Alliance of State and Territorial AIDS Directors (NASTAD) represents U.S. state AIDS directors (health agency directors who have programmatic responsibility for HIV programs) and strives to facilitate united policy and sound programmatic decision making.

NASTAD’s Global Program works to build the organizational and human resource capacity of its HIV 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, and to strengthen organizational capacity for sustainable programs.

NASTAD’s Global Program has extensive experience supporting countries to design and implement HIV surveillance systems, including case-based surveillance systems. The methods that NASTAD uses include:

- Knowledge Transfer for Sustainability
While NASTAD has content and process expertise, and has the ability to support development and implementation work, all work is planned and put into action in close collaboration with the local MoH. NASTAD is committed to local sustainability and indigenous expertise, and works to ensure both through clearly defined training, targeted technical assistance, and side-by-side applied capacity building.

- Training & Operational Support for Local Design and Ownership
To support knowledge transfer and capacity building, NASTAD provides formal and informal training related to HIV surveillance system and process design and implementation. Following data collection, NASTAD will extend this to include training and support for data analysis, data presentation and summarization, and the use of data for program planning and decision making.

- Product Development
  - Case report forms
  - Case surveillance database
  - Case surveillance SOPs and training materials
  - Case surveillance M&E framework and tools
  - Standard data reports