TECHNICAL BRIEF

HIV PATIENT MONITORING AND CASE SURVEILLANCE

ADAPTING AND IMPLEMENTING NEW RECOMMENDATIONS ON HIV CASE SURVEILLANCE

2017

World Health Organization

The tools and recommendations for HIV case surveillance in the 2017 WHO *Consolidated guidelines on person-centred HIV patient monitoring and case surveillance* should be adopted and customized to fit the specific setting of each country and programme; most importantly, to support programme improvement, strengthen linkages in the cascade of care and optimize health outcomes.

ASSESS THE HIV SURVEILLANCE SYSTEM USING A SITUATION ANALYSIS TOOL (ANNEX 3.5.2)

- Review and identify the gaps in policies for HIV disease notification in the country, i.e. laws, policies and regulations for disease notification and relating to data use, security and confidentiality of information collected. Assess the pathway (active, passive or programmed systems) for reporting HIV, other conditions and sentinel events from patient care sites and health facilities, e.g. where patients are diagnosed or receive care, laboratories that conduct HIV diagnostic, viral load and CD4 tests, and vital statistics registries.
- Review the organizational structures for disease surveillance, reporting pathways, processes, forms, data management and dissemination. Assess the potential for using the existing systems, or building upon them, and estimate the costs of developing or strengthening HIV case surveillance.
- Review, update or develop the data collection tools used by HIV testing, care and treatment programmes, laboratories that conduct HIV-related tests and vital registration systems to determine the availability and accessibility of data required for surveillance.

- Assess data gaps or weaknesses that need to be addressed in the HIV case surveillance system, including the data needed for strategic planning, and for measuring HIV prevalence and the effectiveness of the care cascade.
- Assess existing HIV patient and programme monitoring and reporting systems, and how these can be leveraged.
- Assess the potential for electronic medical records, patient registers and laboratory information systems to transmit data directly to the surveillance programme.
- Assess the interoperability status of existing data and information systems and data repositories, and what would be needed to ensure full interoperability of these systems.

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- Review vital registration systems to understand the completeness of death ascertainment, recording of causes of death and accessibility of vital data.
- Assess technological capacity, infrastructure and systems that may facilitate or impede HIV case surveillance.
- Assess feasibility, costs, barriers and needs, such as human resource and training needs, and additional infrastructure needs, including where the country is in transitioning from paper to electronic systems and to the use of unique patient identifiers.
- Ensure national leadership of the surveillance programme (e.g. responsible officials with oversight from a national surveillance working group), and designate officials responsible for surveillance at reporting sites.
- Identify priority areas for investment.

SPECIFY DATA REQUIREMENTS FOR SURVEILLANCE AND DEVELOP TOOLS

- **HIV diagnosis and building on patient monitoring.** HIV case surveillance should start with a diagnosis of HIV and build on existing patient monitoring systems. *WHO provides guidance on HIV case definitions.*
- **Standardization.** Countries should collect a minimum, standardized set of core indicators on six key sentinel events described in the guidance, i.e. first positive HIV test indicative of HIV diagnosis; entry to care; first CD4 test; initiation of antiretroviral therapy (ART); viral suppression and death. Additional events for surveillance of HIV in children include pregnancy in women living with HIV; HIV-exposed infants; infant antiretroviral (ARV) prophylaxis and infant polymerase chain reaction (PCR) tests. *WHO provides guidance on selection of sentinel events.*
- **Key population data.** Routinely collected data can be used to describe access to services by key populations; however, confidentiality and security issues are paramount when collecting these data. In most settings, patient monitoring records should not include the key population category, and any information collected should be used to support patient management and referral to care rather than programme monitoring. The probable route of transmission can be assessed at the point of diagnosis and used to disaggregate data in HIV case surveillance systems.
- **Case report forms** must include sufficient information for surveillance programmes to describe the HIV epidemic according to person, place and time. Information collected should include basic demographic data, facility information and information related to the sentinel event(s) being reported. *WHO provides a model case report form.*
- **De-duplication of records.** Because reports regarding the same individual are likely to be submitted from multiple sources, the surveillance programme must be able to identify reports that concern the same individual across sources and link these reports – preferably using a unique identifier – into a single, longitudinal case record. *WHO provides guidance on such approaches.*

IMPLEMENT, IMPROVE AND SUSTAIN THE SURVEILLANCE SYSTEM

- Key principles of implementing the **data management system** are that the system should:
  - be fully accessible to authorized surveillance personnel;
  - be built with accessible and modifiable software;
  - have local information technology support for troubleshooting and updating the databases and software used;
  - be as simple as possible to meet surveillance requirements;

- collect and link multiple reports concerning individual cases;
- have adequate confidentiality and security protection;
- incorporate automated and manual data quality checks;
- be able to accept, clean and store data, and export data for analysis;
- support transfer between the subnational and national levels;
- be compliant with national laws and policies governing the handling of public health data;
- ensure that data collected at these sites are compatible with the case report form in countries where most HIV testing and care occur in public health facilities that use standardized data collection tools; include interoperability for electronic uploads;
- have data standards and a data dictionary;
- be developed and managed by skilled individuals or commercial suppliers; and
- ensure that confidentiality and security are considered at each step in the system design.

- **Invest in data systems and interoperability.** Countries should invest in robust and secure data systems. As this is done, strengthen the interoperability of electronic databases and elect open-source standards for data systems. *WHO recommends that 5–10% of programme budgets be used to strengthen monitoring and evaluation.*
- **Data quality.** Case surveillance systems must be routinely monitored and comprehensively evaluated at least annually (ideally every six months) to ensure that the surveillance processes are effective and that the data are of high quality. *WHO provides guidance on performance methods and outcome standards for monitoring and evaluating case surveillance.*
- **Strengthen and differentiate data security.** Countries should assess and differentiate between the security of data elements, and invest in robust databases and laws and policies to protect security and confidentiality based on risks and benefits in individual settings. *WHO provides the major headings to be included and refers to additional specialized guidance.*
- **Transition progressively from paper-based to electronic patient information systems.** Countries should use a tiered approach to when and how patient and case monitoring data from paper tools are entered electronically based on resource availability by site or setting, starting with high-volume sites, e.g. with more than 2000 patients. *WHO provides an example of a tiered approach.*

ANALYSIS, INTERPRETATION AND PRESENTATION OF HIV CASE SURVEILLANCE DATA

HIV case surveillance data must be able to describe the sociodemographic characteristics and risk factors that can identify the mode of transmission, the geographical distribution of disease, and how these change over time. The data can be used to strengthen prevention and treatment activities in areas where most cases are being diagnosed and to identify where the HIV epidemic is concentrated. Data from surveillance systems may also be combined with other information on the HIV epidemic, including data from programme monitoring, qualitative studies, vital statistics, censuses, sexually transmitted infections, and surveys to account for changes in the epidemic.

A range of analytical techniques can be employed to correlate data from surveillance with other data through triangulation, data synthesis and second generation surveillance. Because HIV case surveillance systems collect longitudinal data on individuals, they provide important opportunities for analysis of the HIV care cascade indicators, enabling gaps in the cascade to be investigated and addressed. *The guidelines discuss approaches to data analysis and formats for data presentation, including factors influencing the use and interpretation of data (Section 3.6).*

SUPPLEMENTARY OPERATIONAL GUIDANCE

The guidance on HIV case surveillance is supplemented by an online implementation tool (Annex 3.1: HIV case surveillance toolkit – http://www.who.int/hiv/topics/me/en/ that describes the building blocks of an effective case surveillance system, and provides operational guidance to assess current surveillance systems, and plan and implement new or upgraded systems.

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