Surveillance of the HIV/AIDS epidemic: a comprehensive package

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1. Introduction

HIV surveillance is the cornerstone of our understanding of the HIV epidemic. The diversity of the HIV epidemic across geographic regions, populations and time has necessitated robust and comprehensive surveillance efforts that have continued to evolve as the HIV epidemic has progressed.

In 2000, the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) developed second-generation surveillance guidelines, which encouraged the expansion of HIV surveillance activities. These guidelines recommended the use of a variety of data to obtain a more complete picture of the HIV epidemic, and promoted the adaptation of the HIV surveillance system to the type and stage of the HIV epidemic.

Since 2000, the second generation surveillance strategy has been promoted to tailor surveillance systems to the epidemic state of a country. The strategy recommended:

- concentrating resources where they will yield information that is useful in reducing the spread of HIV and in providing care for those affected
- concentrating data collection in populations most at risk of becoming infected with HIV, including men who have sex with men (MSM), female sex workers (FSW), people who inject drugs (PWID) or young people at the start of their sexual lives
- building up information systems that monitor trends in HIV prevalence and sexual or drug injecting behaviours and impact of interventions
- making the most effective use of other sources of information, such as communicable disease surveillance and reproductive health surveys, to increase the understanding of the HIV epidemic and the behaviours that spread it.

HIV surveillance systems continue to change to adapt to new insights and to respond to the greater need for accountability resulting from the increased funding for HIV/AIDS. Furthermore, the landscape of HIV interventions since the year 2000 has changed significantly and programmes like PMTCT and ART have expanded in all countries, though at different rates.

Taking into account these changes the UNAIDS/WHO Global HIV Surveillance Working Group has produced a new comprehensive package for Second Generation Surveillance. This comprehensive package presents modules that address different issues and components of HIV surveillance.

The package includes the following modules:
- Module 1: Guidelines for second generation HIV surveillance: an update: Know your epidemic
- Module 2: Guiding principles on ethical issues in HIV surveillance
- Module 3: Guidelines for assessing the utility data from prevention of mother-to-child transmission (PMTCT) programmes for HIV sentinel surveillance among pregnant women
- Module 4: Surveillance of HIV infection using HIV case notification
- Module 5: Paediatric HIV surveillance among infants and children less than 18 years of age
- Module 6: Guidelines for HIV mortality measurement
- Module 7: Evaluating a national surveillance system
Module 1: Guidelines for second generation HIV surveillance: an update: Know your epidemic

Topics covered

This update provides surveillance tools to monitor the HIV epidemic more effectively. It provides the basic framework and concepts to design an appropriate HIV surveillance system adapted to the country context and situation. In order to get a sense of the epidemic trends, the module makes recommendations to policy makers and provides additional data collection tools to strengthen on-going surveillance systems.

The module approaches HIV surveillance in a systematic manner, starting with identifying epidemic hotspots in countries to create a national picture of the HIV epidemic. The development of a comprehensive surveillance system is then discussed, based on epidemic level and existing systems and data sources. Finally, the module describes the use of surveillance data to predict biological and behavioural trends and improve programmes.

When and where to use

This module is applicable for all countries and epidemic levels. It is addressed to decision makers, HIV surveillance officers and multi- and bilateral donors.

Module 2: Guiding principles on Ethical issues in HIV surveillance

Topics covered

HIV surveillance should be implemented taking into account some basic ethical principles. This module provides guidance points that should be discussed and reviewed in countries when undertaking HIV surveillance activities.

The guidance points presented here do not represent strict prescriptions but rather discuss the ethical issues that need to be considered when conducting second generation surveillance. They cover activities such as serological surveys with linked or unlinked HIV testing and testing for sexually transmitted infections, as well as behavioral surveys on sexual behaviours or illicit drug injecting behaviours. This document gives a brief background on past ethical considerations and then provides specific guidance points to address these issues. The discussions build on the purpose and history of HIV surveillance and its conduct. The document considers the links between the technical and ethical aspects of HIV surveillance and ensuring protection for human subjects, and then formulates guidelines that account for the context in which surveillance systems are implemented.

When and where to use

This module is applicable for all countries and epidemic levels. It is addressed to policy makers, HIV surveillance officers and development partners working in HIV surveillance.

Module 3: Guidelines for assessing the utility of data from prevention of mother-to-child transmission (PMTCT) programmes for HIV sentinel surveillance among pregnant women

Topics covered

The purpose of this guidelines is to provide information for countries that want to use prevention of mother-to-child transmission (PMTCT) programme data for HIV surveillance.

The module provides guidelines as to the feasibility of transitioning from a primarily antenatal care (ANC) sentinel surveillance (SS)- based surveillance system to the use of PMTCT programme data. This guidance describes how to assess the state and content of PMTCT programme data for use in HIV surveillance and recommends criteria for comparing HIV estimates from ANC SS and PMTCT programme data. The guidance also describes how to conduct data quality assessments of PMTCT data, as well as PMTCT HIV testing quality assessments.

When and where to use

This guidance document is addressed to national AIDS programme managers and epidemiologists responsible for monitoring HIV trends in resource-constrained countries. This module is especially directed to countries with generalised epidemics that use ANC surveillance as the cornerstone of HIV epidemic monitoring. In addition, this document is useful for PMTCT and surveillance officers assessing the use of PMTCT data for HIV surveillance.

Topics covered

This module provides guidance to support the improvement of HIV case surveillance, establishing common concepts and standards for HIV case reporting, specifically for Latin America and Spanish-speaking Caribbean countries. The guidance provides an overview of HIV case surveillance systems and ensuring the quality of such systems.

The first part of the module provides a brief background of HIV case surveillance and describes elements of case surveillance systems, including standards and HIV case definitions. The module then discusses overall quality assurance and supervision of the case surveillance system, as well as data analysis and interpretation and ethical considerations.

When and where to use

This module is relevant to all epidemic levels in Latin American and Spanish-speaking Caribbean countries. It is addressed to HIV surveillance staff at local, regional and national levels, as well as international partners and agencies that use or support HIV surveillance in countries.

Module 5: Paediatric HIV surveillance among infants and children less than 18 years of age

Topics covered

HIV surveillance data on infants and children are sparse in many countries. The data that exist are generally limited to in-utero exposure and intrapartum infection, with some survival data for children infected with HIV through mother-to-child transmission. The lack of data hampers prioritization and scale up of HIV prevention and care for children and results in a gap that requires urgent attention.

The overall goal of this module is to provide guidance to countries on conducting paediatric HIV surveillance routinely, either as specific paediatric-focused activities or as essential components of broader surveillance efforts, to understand the HIV epidemic in paediatric populations. This guide provides different strategic approaches to measure the burden of paediatric HIV according to country-specific HIV epidemic contexts. The module includes discussions on ethical considerations, developing a pediatric surveillance strategy, and ensuring the quality of the pediatric surveillance system.

When and where to use

This module is applicable for all countries and epidemic levels. It is addressed to decision-makers, HIV surveillance officers and development partners working in countries that need to improve HIV surveillance among children.

Module 6: Guidelines for HIV mortality measurement

Topics covered

Decreases in HIV mortality are among the clearest indicators of the success of HIV prevention, care and treatment programmes. However, HIV mortality data in most countries are lacking. This module provides guidance on surveillance activities to measure HIV mortality, addressing short- and long-term goals. Short-term goals focus on obtaining direct measures of HIV mortality, while long-term goals identify opportunities and strategies for health systems strengthening and creating civil registration systems.

The first part of the guidance reviews the different methods and tools for measuring HIV mortality, and the strengths, limitations and opportunities for each method. The second part of the guidance presents the criteria, methods and tools that can be used for HIV mortality data collection in two HIV epidemic contexts: low-level/concentrated epidemics and generalized epidemics. This module provides guidance to countries on different approaches to measure the burden and impact of HIV mortality according to country-specific situations.

When and where to use

This module is applicable for all countries and epidemic levels. It is addressed to decision-makers, HIV surveillance officers and development partners working in countries that need to improve HIV/AIDS mortality surveillance.

Module 7: Evaluating a national surveillance system

Topics covered

HIV surveillance systems need to be evaluated regularly. This module provides a framework on how to assess and evaluate HIV surveillance systems and adapt them to the needs of countries.

The module describes how to conduct internal and external evaluations using a standard approach to assess the overall effectiveness of existing surveillance systems. The module includes a rationale for conducting surveillance evaluations and systematically describes how to plan and conduct evaluations. The process starts with inventorying current surveillance activities, followed by assessing the design and implementation of these activities. The evaluation of a variety of surveillance activities is presented, with questions and checklists specific to each type of activity. An assessment of the analysis and use of surveillance data is discussed as the final evaluation step. The module also includes case studies from two surveillance evaluations.

When and where to use

This module is applicable to all countries and epidemic levels. It is addressed to HIV surveillance officers, consultants and partners in HIV surveillance.

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