

WHAT'S NEW IN PERSON-CENTRED HIV PATIENT MONITORING AND CASE SURVEILLANCE

2017



The 2017 WHO *Consolidated guidelines on person-centred HIV patient monitoring and case surveillance* aim to help countries to implement WHO strategic information indicators for HIV (1) and WHO guidance on the use of antiretroviral drugs for HIV treatment (2) into routine HIV patient monitoring and health information systems.

The guidelines support the definition of standard events along the cascade of services; the linkage of key data sources to support the cascade of services; and the development of routine, ongoing monitoring systems for improved patient care, programme management and reporting on most programme, national and global indicators.

MAJOR RECOMMENDATIONS IN THE GUIDELINES AND COUNTRY EXAMPLES

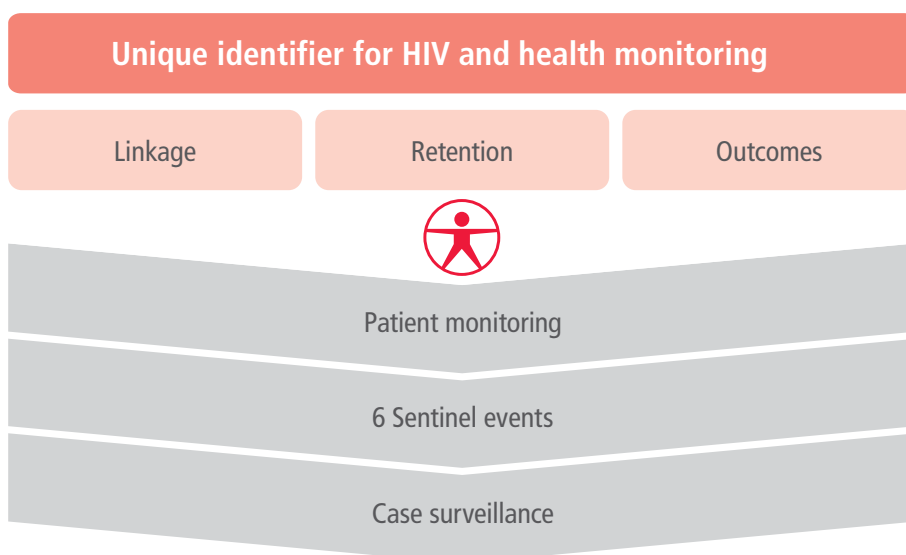
KEY RECOMMENDATIONS

- [1] **Minimum dataset for patient care.** Countries should collect a minimum, standardized set of data necessary for the care and management of persons confirmed to be HIV-positive, a subset of which can be used to report on district, national and global indicators for programme monitoring and management. *WHO provides guidance on a minimum dataset for patient monitoring that reflects updates of the ARV guidelines.*
- [2] **Transitioning to “treat all”.** Consistent with “treat all” and depending on national guidelines, once 90% ART coverage has been attained, countries should transition from using the pre-ART register and collecting HIV care indicators (e.g. indicators from the consolidated strategic information guidelines LINK.2 HIV care coverage, LINK.3 Enrolment in care) to using the ART register and dropping HIV care indicators from reporting requirements. *WHO provides guidance for this transition.*



- [3] **Simplification of tools.** For paper-based systems, patient monitoring tools (cards, registers and reports) should be simplified and standardized across facilities. *WHO provides generic tools for adaptation.*
- [4] **Integration and linkages.** Health workers should create an HIV patient card for every person who is confirmed HIV-positive and subsequently enters into care, regardless of the point of entry, and ART registers should be kept and used at all sites where ART is provided. The HIV card should form part of the facility-based patient folder or passport, and should be integrated with primary health care. *WHO provides a generic HIV patient card and ART register for country adaptation.*
- [5] **Data quality review and use for quality of care.** Countries should carry out periodic review of the patient monitoring system to collect key additional national and facility-based indicators (for paper-based systems); monitor and assess the quality of data; monitor and improve the quality of care; and collect facility-level early warning indicators (EWI) for HIV drug resistance (HIVDR). *WHO provides guidance on carrying out an annual patient monitoring review and improving the quality of care.*
- [6] **Standardization of sentinel events and indicators.** Countries should collect core information on a standardized set of sentinel events and indicators, including at a minimum, the six key cascade events described in these guidelines. *WHO provides guidance on key indicators for primarily paper-based monitoring systems and additional indicators for electronic systems or periodic review, especially of patient monitoring tools.*
- [7] **De-duplication of records to support facilities and improve data quality.** HIV case surveillance should provide de-duplicated counts of diagnosed persons and people on treatment for reporting, to be shared with facilities. *WHO provides guidance on these approaches.*
- [8] **Country situation analysis.** Improvements to HIV case surveillance, patient monitoring and unique identifiers should be based on a country situation analysis that identifies and costs incremental improvements. *WHO provides a tool for country situation analysis.*
- [9] **HIV diagnosis and building on patient monitoring.** HIV case surveillance should start with the diagnosis of HIV and build on existing patient monitoring systems. *WHO provides guidance on HIV case definitions.*

FIG. 1. CONSOLIDATED M&E SYSTEM FOR CARE AND REPORTING



[10] Key population (KP) data.

Routinely collected data can be used to describe access by key populations to services; however, confidentiality and security issues are paramount when collecting data related to KP, whether in patient monitoring or case surveillance systems. In most settings, patient records should not include the KP category and any information collected should be used to support patient management and referral to care. The probable route of transmission can be assessed at the point of diagnosis and used to disaggregate data in case-based surveillance systems. *WHO provides guidance on how to address issues around KP data collection and reporting.*

[11] Promote and use unique identifiers

that replace names in HIV patient records shared within the national HIV programme. This anonymous code should be linked to their health records. *WHO provides definitions and examples of unique identifiers.*

[12] 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 will be 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.*

[13] Strengthen and establish different data security levels.

Assess and establish different security levels for data elements, and invest in robust databases and policies to protect security and confidentiality based on risks and benefits in individual settings. *WHO provides the major headings to be included and provides reference to additional specialized guidance.*

[14] Invest in data systems and ensure interoperability.

Countries should invest in robust and secure data systems. As this is being done, strengthen the interoperability of electronic databases and opt for open-source standards for data systems. *WHO recommends that 5–10% of the programme budget be used to strengthen monitoring and evaluation.*

[15] Use individual data to improve programmes and long-term chronic health care. *WHO recommends that data be linked to programme improvements and that evidence of these improvements is collected.*

- **Strengthen retention and transfer** by supporting the routine sharing of information between clinics.
- **Ensure linkage** by supporting the routine sharing of information between testing, treatment, laboratory, pharmacy and other health services.
- **Strengthen integration with long-term chronic health care** by using unique identifiers to share information and link HIV and wider health services.
- **Invest in data analyst capacity**, including central and district data analysts and routine dashboards to feed back data in real time for programme improvement.

EXAMPLES OF COUNTRY EXPERIENCE

Country experience strongly informs the new guidelines and highlights the importance of performing a situation analysis to guide their implementation. Examples of country efforts highlighted in the guidelines include the following:

Country	Current situation	Benefits and next steps
Patient monitoring		
Malawi	Health “passport” for all health services. Differentiated system in which all HIV sites with more than 2000 patients use electronic medical records, but most sites are still paper-based. Data are entered into electronic database centrally.	Validated quarterly reporting from routine system for programme management, and major benefits for drug forecasting. Next step to integrate HIV with national ID and health passport.
Myanmar	Patient monitoring system adapted from generic WHO tools. Patient reporting system initially based on nongovernmental organization (NGO) programmes delivered by Médecins Sans Frontières (MSF).	Strong data on cascade routinely used to highlight gaps and improve late initiation of ART. Facilitates planning and global reporting. Challenge is transition to national system with investments in patient index, interoperability and links to the district health information software (DHIS) 2.
Western Cape, South Africa	Three-tiered patient monitoring system with paper at lowest level, entered into electronic register at district level, and electronic records in 15 sites. Tier.net in 3000 sites, which feeds back to patient management.	Regular, routine reports to facilities on loss to follow up, viral load data to improve patient care and de-duplicate data. Recently developed and implemented integrated (HIV, TB, antenatal care [ANC]) paper-based patient record towards integrated patient care and monitoring.
Zambia	Smartcard system used to link patient records, but does not cover all facilities. Not all facilities linked online; data collected on memory sticks from some sites.	Major benefit of being able to de-duplicate testing and treatment records, for improved patient management and more accurate reporting.
Case surveillance		
Brazil	Case reporting primarily built for payment purposes, not surveillance. Labs require CD4 count and viral load to receive payment from Ministry of Health. Uses names and includes key population information to assess equal access.	Works well and improves follow up and payment. Major limitation is that it does not include private laboratories. Assess access to key populations, ensure confidentiality and human rights protection.
Haiti	Individual case surveillance introduced with single national dataset integrating multiple sources. Data de-duplicated and used to identify transfers. Minimal cost, as built on existing infrastructure and data.	Targeted HIV treatment services as populations migrated seasonally. Better directed prevention resources. Generates routine reporting.
Zimbabwe	Building case surveillance on patient monitoring system. Approximately 80% of records contain a unique national insurance number. Need to invest in national database to link facilities.	Major benefits for retention and contacting those lost to follow up, removing those who have gone to other facilities or who have died.
Unique identifiers		
Botswana	Routine use of national unique identification and insurance number for access to all HIV, health and social services.	Easier access, transfer and linkage to a range of HIV and health services.
Thailand	Unique identifiers used based on social insurance, links key databases for patient management.	Improved availability and speed of transmitting lab test results, improved reimbursement. Gap in migrants not covered by national unique identification.

1. Consolidated strategic information guidelines for HIV in the health sector. Geneva: WHO; 2015.

2. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: Recommendations for a public health approach. Geneva: WHO; 2016.

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TECHNICAL BRIEF

HIV CASE
SURVEILLANCE