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Web Annex H. Considerations for monitoring HIV testing services programmes

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Contents

H.1 Background and purpose

Strategic information is collected to inform policy and programme decisions. This annex provides a brief overview of how strategic information can be gathered to monitor HTS and to assess the effectiveness and efficiency of programmes. The references for this chapter and HIV Department's forthcoming 2020 *Consolidated strategic information guidelines* include comprehensive guidance for monitoring HIV programmes. Much of the information presented here is drawn from these published WHO guidance documents. Appendix 1 includes a list of priority indicators for HTS programme monitoring which was developed in consultation with technical partners, funders, and national programmes.

H.2 Strategic information for HTS

Strategic information for HTS can be collected and analysed for a variety of purposes. Three primary functions include patient monitoring, programme management and programme monitoring.

Patient monitoring

Understanding the HIV testing history, patterns of testing, retesting and test results is necessary to guide the provision of support and clinical care to patients. Patient monitoring systems, whether paper-based or electronic, can enable effective clinical management and generate data for programme monitoring. HIV programmes should promote patient monitoring approaches that are inclusive of all feasible and appropriate prevention, HTS and ART service delivery points to support collection of comprehensive patient data and support linkage.

Programme management

Aggregation of individual-level data provides insight into HTS programme activity, its efficiency, gaps and outcomes to guide decisions on resource allocation and to identify priorities and deficiencies in service provision that need to be addressed. This includes HIV case surveillance.

HIV case surveillance refers to the systematic reporting and analysis of standardized information about cases diagnosed with HIV to a public health agency responsible for HIV prevention, control and action. Case surveillance is also known as case reporting.

Programme monitoring

For the purpose of accountability, HTS data are required that report against national and global targets. These might be targets outlined in national strategic plans or for reporting as part of global monitoring activities, such as the Global AIDS Monitoring (GAM) to track progress in achieving goals, meeting commitments and policy development.

WHO recommended indicators for programme monitoring are included in Consolidated HIV strategic information guidelines: driving impact through programme monitoring and management(1).

H.3 Data sources

Information relevant to HTS programmes can be gathered from a broad range of sources. It includes both programme data and data collected through surveys. Mapping available data sources can be useful, noting, the completeness of each and determining their relevance at the patient-level, programme management level and/or programme monitoring level.

H.3.1 Programme data

Data collected routinely in the course of HTS provide critical strategic information. The diversity of contexts in which testing occurs have important implications for the collection, aggregation and analysis of data.

First, HIV testing is delivered in a wide variety of settings, across a range of primary, secondary and tertiary health-care services that include sexual and reproductive health, family planning, antenatal and other outpatient clinics, inpatient facilities such as infectious disease units and emergency departments, community settings and even at home, with HIV self-test (HIVST) kits.

Second, approaches to HIV testing vary: tests might be offered to all people attending a service or to certain people or populations selectively, based on symptoms or conditions associated with HIV; based on reported or potential risk; in the context of partner services or people identified through social network-based approaches; as part of prevention programmes, including PrEP and voluntary male medical circumcision (VMMC); and for retesting people at ongoing high risk of HIV exposure.

Data collection practices and completeness of records may vary across these different settings and testing approaches. Where possible, HIV testing information should be collected in a standardized manner across all service sites, both facility- and community-based. At a minimum the following information should be recorded:

- HIV test date
- HIV test result
- date of diagnosis
- date that patient received the result
- linkage to care where feasible and appropriate.

Data collection systems can be paper-based or electronic, possibly part of a larger electronic medical record (EMR) system. Paper-based systems are typically limited in the amount of information that can be captured or later transferred to a reporting system to collated for aggregate reporting. Furthermore, collecting information on multiple patient characteristics in a paper-based system can be costly and time-consuming. Accordingly, the data collected should be only the most relevant and important to the local context. Countries with paper-based systems are encouraged to plan and allocate resources for a progressive transition to electronic patient information systems. Paper-based systems may need to prioritize specific disaggregations relevant to programme priorities and targets, such as age or type of entry point, to maintain data quality.

In some countries HIV is a notifiable condition, along with other infectious diseases of public health significance, and reporting new diagnoses to a national register is required by law.

Programmatic HIV self-testing data

In different settings HIVST kits may be accessible from a variety of venues and service delivery mechanisms. Programmes providing HIVST kits should develop data collection systems that capture the number of self-testing kits distributed, with disaggregations including age, sex and type of distribution. Some programmes are using population-based surveys and quality improvement tools to improve monitoring of test results, knowledge and awareness, potential harm and linkage.

Complementary approaches, such as reviewing broader programme results by setting and population where HIVST implementation is focused, may also be helpful – for example, examining whether there is a change in HTS and ART uptake by population group, including in log-books or intake forms if a person has ever tested or self-tested before, and assessing whether there is a change in the proportion of people with HIV identified at HTS sites. However, programmes using log-books to track self-testing uptake and linkage need to exercise caution, if they require individuals or couples to disclose whether they self-tested before coming to a facility, there may be substantial underreporting as a result.

Programme support tools such as hotlines and social media messaging services have also provided additional information and are currently being pilot-tested in many settings. For example, in South Africa the national counselling hotline staff have been trained to support people who self-test for HIV and to provide accurate information. The hotline collects the number and nature of calls quarterly. Also in South Africa, a pilot using a social media messaging service is underway. To date, the service has been able to provide information on the test results and linkage reported by self-testers who use the messaging service. In contrast to research, which usually is limited to a defined area and time span, routine tracking of HIVST uptake, test results and whether people link to care is challenging and requires significant resources. Also, increased or more detailed tracking may affect the uptake of HIVST, as many people opting for this approach are not accessing existing HTS because they may want to seek a more private or confidential way to learn their status.

Data from community-based venues providing HTS

Just as community-based services make an essential contribution to HIV testing coverage, so, too, are data on community-based services crucial to HTS programme statistics. Community-based venues may focus on providing services for people from key populations. Data from these venues provide an important source of information on this crucial clientele. Depending on how closely community-based venues are integrated with HIV treatment and care services, capturing information on linkage-to-care may be challenging. In the absence of comprehensive EMR systems, paper-based appointment reminder and linkage registers can be used to monitor referral and linkage between testing and ART services.

Patient-centred monitoring and case-based surveillance

Patient records and data collection systems that use some form of unique identification (or unique identifier code [UIC]) across testing, care and treatment services can enable tracking of patients along the continuum of care from diagnosis, enrolment in care, uptake of and retention on treatment through to viral load testing and viral suppression. Such systems can provide benefits for people receiving services, discriminate between individuals and avoid duplication and double counting *(2)*.

Aggregating programmatic data

For programme management and monitoring purposes, individual-level HTS data are collated and aggregated to produce important summary information.

If data collection is not standardized across HTS providers and approaches, combining data from multiple sources can be challenging. For example, the type of data and manner in which they are collected and recorded may differ between government-run facilities and community-based HTS services. For data to be aggregated by programmes, data from different sources often needs to be cleaned and transformed.

Incomplete or absent data should be identified and accounted for to allow for correct interpretation. For example, if data on testing by community-based organizations or through outreach is not available or not collected, then the total number of tests conducted will be unknown. When deriving estimates of HTS relative to the population in need, the correct denominator relevant to the available numerator (data on tests conducted) should be used.

Accounting for retesting is also important when aggregating and analysing programme data. People may test multiple times within a time period for a variety of reasons: (i) those who face ongoing risk of HIV infection (for example, men who have sex with men engaging in condomless sex or those receiving PrEP); (ii) as a re-test test after an HIV-inconclusive test result; (iii) to verify an HIV-positive diagnosis before initiating ART; (iv) inadvertent retesting of persons with known status. As a result, the number of tests performed in a given period is more than the number of indivduals tested; both should be reported.

Some data may useful at a site level but not be appropriate for aggregation at national or global levels – for instance, monitoring the retesting of people who self-report an HIV-negative status. While this information could be helpful at a site level to understand the number of people who are first-time or repeat testers, because this information is self-reported, and because people retest with varying frequency depending on personal risk and other factors, aggregating these data can be challenging in the absence of electronic systems with unique identifiers.

Confidentiality in programmatic data collection

Confidentiality of information and data security are essential. This is particularly the case when information is linked or shared across different programmes and service providers, and when the information is sensitive, such as HIV status or information on key population status and other stigmatized behaviours or characteristics. Programmes that deliver partner services, including social network-based approaches, must also actively ensure confidentiality of client and partner data as well as personal and medical information. Policies, regulations, standard operating procedures and technical measures must be in place at all levels of the health information system to protect patient confidentiality *(2)*.

> Programmes that deliver partner services must ensure the confidentiality of client and partner data as well as clients' personal and medical information.

Assessing data quality

Reliable strategic information depends upon high-quality data information systems and processes. Data systems are subject to various limitations such as missing values, biases, measurement error and human error in data entry and computation. It is important to undertake assessments of data quality to understand these limitations and to confidently interpret strategic information on HTS (3). Data quality review can be undertaken routinely in the following ways: routine reviews of data quality can be part of a feedback cycle that identifies errors in near real-time so they can be corrected as they occur; an independent assessment of a core set indicators to identify gaps and errors in reporting and periodic in-depth reviews of data quality that focus on a specific programme area.

Data for quality improvement

Programme data are critical to monitoring quality, quality assurance and quality improvement processes. Chapter 9 describes approaches to quality assurance for HTS. Further information on using data for quality improvement can be found in *Maintaining and improving quality of care within HIV clinical services (4)*.

Quality improvement is a means to continually improve performance as part of a routine process, generally applied by health facility teams within a national quality improvement programme and designed to test changes in programme services, continually measure the effects of these changes and use data to address gaps and improve clinical performance and health outcomes over time.

H.3.2 Survey data

Surveys can provide valuable information on access to HTS, attitudes to testing and behaviours. Surveys can be particularly helpful in gathering information on testing among key populations that might be otherwise difficult to learn from programmatic data. Surveys may be undertaken at health facilities such as sexual health clinics, or in community settings, which may reach people from specific, underserved and vulnerable populations.

An understanding of HIV testing patterns can be obtained through survey questions regarding HIV testing behaviour (such as frequency and mode of HIV testing), alongside other behavioural information (for example, sexual behaviour and drug and alcohol use). Surveys can also offer opportunities to better understand the acceptability of new technologies such as self-testing.

Population-based surveys that are representative and appropriately powered can be used to assess how many people have ever tested for HIV, tested positive, where they tested (including HIVST) and other HIV testing behaviour. These surveys can provide an approximation of the frequency of testing and retesting and may be particularly helpful to determine, overall, the proportion of people with HIV who know their status (the first "90") and testing coverage among hard-to-reach populations *(5)*.

Biobehavioural surveys, which involve collecting a biological sample to be tested for HIV, can provide independent evidence of HIV prevalence and the extent to which testing programmes are reaching priority groups and the general population. Comparison with self-reported HIV status can be used to measure the extent to which those living with HIV have been diagnosed with HIV. Where appropriate incidence tests are used, the results can provide insight on new infections as well as the proportion who are unaware of their HIV infection *(6)*.

It is important, however, to emphasize that, depending on the sample size and sampling strategy employed, survey findings may have limited generalizability and should be interpreted cautiously. Also, surveys are resource-intensive, and it may take several years before survey results are available. For this reason, they are often conducted only periodically (for example, every 3–5 years) and may focus on a single key population in each cycle.

H.4 Disaggregating data on HTS

Disaggregating routinely collected HTS data provides evidence for fine-tuning HTS operations. Particularly valuable disaggregation can include breaking down data according to service delivery approaches, testing modalities, priority groups and key populations. The following disaggregation should be prioritized:

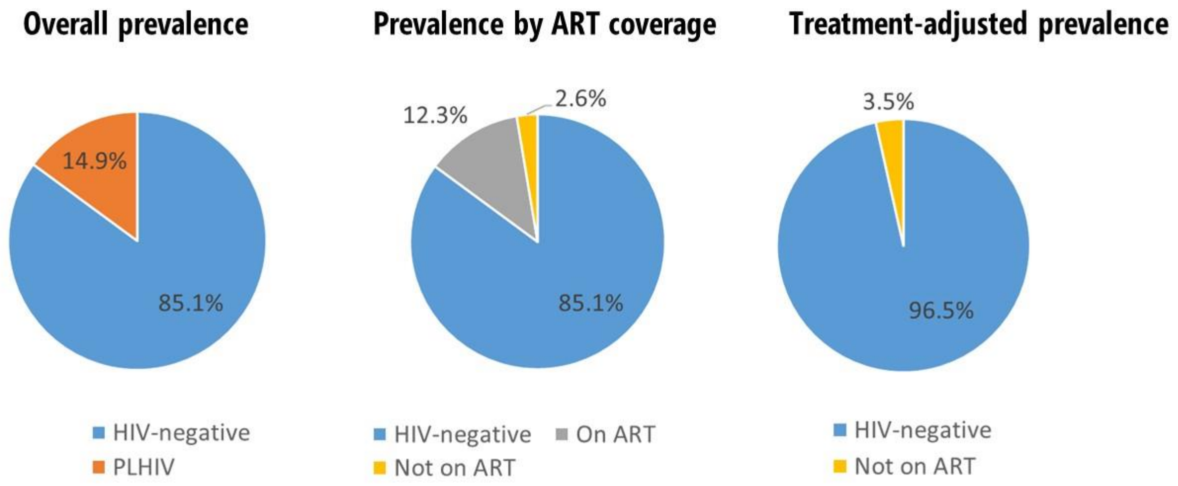
- **Age**. Five-year age bands are suggested: 0–4, 5–9, 10–14, 15–19 (or 15–24), 20–24, 25–29, 30–34, 35–39, 40–44, 45–49, 50+. At a minimum, age should be disaggregated into two categories – those ages 15 years and less and those older than 15 years). In some circumstances rates of positivity will be influenced by the age distribution of those tested. For example, if testing is scaled up among children younger than 15 years with low risk of HIV infection, positivity can be expected to be low in this group and lower overall.
- **Sex**. To detect differences in access to treatment and infection rates between men and women.
- **Key populations.** These include men who have sex with men, people who inject drugs, people in prisons and other closed settings, sex workers and transgender people.
- **Other priority groups.** Women attending antenatal care, sexually transmitted infections patients, persons attending tuberculosis (TB) clinics, as well as those with TB symptoms (also called presumptive TB patients) or diagnosed with TB, and women attending family planning services in high HIV burden settings.
- **Geographical location**. By relevant subnational administrative categorizations.
- **HIV testing provider/venue/modality.** Facility- or community-based testing; self-testing; partner services/provider-assisted referral/social network-based HTS.
- **Retesting.** To account for individuals regularly accessing HTS, particularly those retesting because they face an ongoing risk of HIV infection.

H.5 Treatment-adjusted prevalence

To set HTS targets that are both ambitious and attainable, programme managers need to quantify HIV prevalence excluding those on ART from both numerator and denominator – a concept known as "treatment-adjusted prevalence". The assumption is that HTS are not testing those already on ART, but rather they are serving the remaining population, those with unknown or previously negative HIV status. Over time, this indicator gauges progress in reaching people with HIV who do not know their status and are not on ART. Review of present day treatment-adjusted prevalence can provide useful insight for HIV programme managers seeking to understand positivity in HTS.

Fig. 10.1 illustrates the relationships among overall prevalence, prevalence of ART coverage and treatment-adjusted prevalence. The comparison highlights the potential for low positivity in HTS in the context of high ART coverage and, thus, the need to focus on the untested segment among those who are HIV-positive. This is the principle, around which the concept of treatment-adjusted prevalence was formed.

Fig. H.1. Treatment-adjusted prevalence in women ages 15–49 in a country X



H.6 Indicators

WHO recommends a selected group of indicators and disaggregation for monitoring HTS programmes. These indicators may be used for patient monitoring, programme management and programme monitoring. These recommended indicators are aligned with indicators included in the GAM process *(7)* and consistent with WHO strategic information guidelines for HIV in the health sector *(8)*. The recently updates consolidated strategic information guidelines, provides detailed indicator descriptions(1). Indicators can provide critical information at several levels:

- At the service delivery level, clinicians and funders need information for both day-to-day management of patients and long-term planning and funding of relevant services.
- At the national and subnational levels, health programme managers need reliable and timely information to identify needs and effective ways of responding to them. They use strategic information to assess whether programmes are on track in terms of access, coverage, quality and equity and to guide corrective action where needed.
- At the global and national levels, ministries of health and intergovernmental agencies report on progress towards specific targets. Funders use strategic information to make evidence-based decisions about where to invest resources and how to fill gaps. Managers and decision-makers use data to plan and coordinate health interventions from a national, regional or global perspective.

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