



Guidance Note

HIV Surveillance Options for Key and Vulnerable Populations in Global Fund Grants

Allocation Period 2023-2025

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Introduction

This guidance note facilitates the discussion with principal recipients and in-country partners during funding request development, grant-making and impact assessment, applicable to country-specific or regional grants with components targeting key populations. It aims at addressing practical questions raised frequently from the public health and monitoring evaluation specialists in the country teams but not addressed in the existing WHO/UNAIDS guidelines on HIV surveillance and surveys for key populations.

Ethical Considerations

The basic principles of ethical medical research should be applied in HIV surveillance and surveys, programmatic mapping and size estimation: individuals should be respected; all efforts should be conditional to informed consent; the endeavour should provide benefits and must have community buy-in, approvals, and careful consideration of the legal and societal environments. Drawing attention to stigmatized populations has the potential to create harm. In this regard, the principles outlined in the Helsinki Declaration should always guide any surveillance efforts: the rights of patients including those who are involved in medical research, the rights and interest of individual research participants should be the primary consideration; medical research need to promote and ensure respect for all humans and protect their health and rights; and all vulnerable groups and individuals should receive specifically considered protection to ensure that no harm is done (World Medical Association Declaration of Helsinki, as revised in 2013).

Key and Vulnerable Populations

Broadly speaking, key populations in the context of HIV/AIDS are those that experience a high epidemiological impact combined with reduced access to services and/or being criminalized or otherwise marginalized.

For the purposes of this document, a group will be deemed to be a key population if it meets all three of the criteria below:

- Epidemiologically, the group faces increased risk, vulnerability and/or with request to at least one of the three diseases – due to a combination of biological, socioeconomic and structural factors;
- Access to relevant services is significantly lower for the group than for the rest of the population. Dedicated efforts and strategic investments are required to expand coverage, equity and accessibility for such a group.
- The group faces frequent human rights violations, systematic disenfranchisement, social and economic marginalization and/or criminalization, which increases vulnerability and risk and reduces access to essential services.

Based on these criteria, key population groups include sex workers (male or female or transgender women), men who have sex with men (MSM), people who inject (or use) drugs (PWID or PWUD) transgender persons and prisoners.

Other vulnerable groups such as miners, truck drivers, refugees, people with disabilities, TB patients, migrants, fishermen may be considered based on the criteria mentioned above and supported by the evidence of increased HIV transmission risk.

Public Health Surveillance

Public health surveillance is the continuous and systematic collection, analysis and interpretation of health-related data needed for the planning, implementation and evaluation of public health practices. Its purpose is to:

- Serve as an early warning system for impending public health emergencies.
- Document the impact of an intervention, or track progress towards specified goals.
- Monitor and clarify the epidemiology of health problems, to allow priorities to be set and to inform public health policy and strategies.

Surveillance of and surveys on HIV and other sexually transmitted infections (STI) are the major data sources for HIV prevalence, STI prevalence, risk factors and behaviours, coverage of interventions and its impact. There are several types of surveillance and/or surveys:

- HIV sentinel surveillance
- HIV sentinel surveillance plus (with some behaviour components)
- Integrated bio-behavioural surveys (IBBS)
- National population-based household surveys
- Programmatic mapping and size estimation exercises

HIV surveillance and surveys should be complementary to a routine case surveillance system. Whenever possible, data should be disaggregated by sub-groups within key populations, for example, by age groups, people who inject drugs by gender, sex workers and MSM who also inject drugs, etc.

The sampling methods used include cluster (household-based) sampling, convenience and snowball sampling, respondent driven sampling, time-location sampling, etc. The choice of sampling methods depends on whether the group is hidden or hard to reach, catchment area, pre-existing aggregation, resources available, local implementation and analysis capacity. All approaches mentioned in this paper require informed consent, return of HIV and other biomarker results, and take into account gender considerations. For example, PWID are usually mostly males, but female PWID play a critical role in transmitting HIV, as many of them are sex workers also.

Use of surveillance data should be in combination with programmatic results, such as HIV counselling and testing, PMTCT, ART, blood screening, etc. Increasingly and where possible, programmatic results should be used for surveillance purposes to monitor the trend and impact. Data quality should be assessed before any analysis is undertaken in order to understand the potential limitations of data sources and methods. Networks of key populations and other stakeholders should be involved at all stages, in assessing the need, survey method, data collection and analysis. These groups are also key to the interpretation of findings and the design, implementation and evaluation of programs.

HIV/AIDS Case Surveillance

HIV/AIDS case surveillance captures the case information from all sources where HIV testing service is provided. It captures all HIV infections, irrespective of clinical staging, with demographic information (usually names or unique identification code, age and gender and basic contact information), categorization of transmission risks (heterosexual, homosexual, mother to child, blood borne such as unsafe injection drug use or unsafe blood/blood product transfusion, etc.), clinical staging and/or CD4, whether on ART and in some cases viral load.

HIV Surveillance Specific for Key and Vulnerable Populations

HIV surveillance specific for key and vulnerable populations includes HIV sentinel surveillance or plus and IBBS.

HIV sentinel surveillance usually includes consecutive/take-all sampling of defined sentinel groups in a defined period of time. Some countries also collect syphilis prevalence data. Groups can be any of the above mentioned. Target sample sizes are estimated based the projected HIV prevalence, and desired precision, usually 300-400 per group and location. The time period for collection is usually a few months. Sampling methods usually include cluster sampling, convenience sampling or snowball sampling. In some cases, data are collected from program clients. Program client data produce strongly biased results and this approach should be discouraged. It has been a common surveillance option for key populations in Asia, Central America (VICITS, acronym for Sentinel Surveillance of STIs and HIV in Spanish language) and Eastern Europe and Central Asia. It can be implemented with minimum financial and human resources. Data analysis is straight-forward but representativeness/generalizability may be biased or limited to the locations sampled.

HIV sentinel surveillance plus adds basic behavioural information to HIV sentinel surveillance. The behavioural information included in the surveillance are limited to a few key variables for each group; the questionnaire is often just half a page long. However, such collection of primary data requires informed consent. Countries like China and Viet Nam have implemented this option. It can be implemented with minimum financial and human resources especially where sentinel surveillance is already routine. Data analysis is easy with similar caveats as above. Population size may be conducted in this system, depending on the sampling method used.

IBBS aim at generating population (not just sample) estimates through the collection of representative samples or samples with known sampling probabilities. Usually respondent driven and/or time-location sampling methods are used. IBBS captures HIV and STI prevalence, behaviours and coverage/use of interventions among a predefined sample size of any of the high-risk groups, every 3 years. Population sizes can be estimated using object and service multipliers built in the questionnaire, or through the use of Bayesian statistics built into the RDS-A software. Relevant variables should be included in the questionnaire and laboratory tests to enable HIV testing and treatment cascade analysis by key population groups. The extended contact time with respondents allows for multiple biological specimen collection and administration of counselling. IBBS has been implemented among sex workers, MSM, PWID, miners, trucker drivers, etc. in many countries. It takes usually 6-9 months, sometimes a year or more from formative research to preliminary report. It is finance-, time- and human resource intensive. The management and analysis of data require trained skills with specialized software (RDS-A, Stata or other statistical packages).

Categorization of Surveillance and Survey Data

The prevalence and/or behavioural data of at least two time points can be categorized as **nationally acceptable** when:

- Survey is performed with a national sampling design, at least two time points, with most recent in the past 3 years; for at least two groups of national interest;
- or having systematically operated, annual or biennial, and nationally representative sentinel surveillance for at least two groups of national interest, and
- half of all first-order subnational divisions (provinces, regions, states, etc) have sentinel surveillance or IBBS sites, even they are all urban (for key populations).

In some cases, the data can be locally acceptable only for those sites where survey or surveillance were conducted. In these cases, the Global Fund works with partners to ensure the funding of additional surveys to provide more nationally representative data.

Extrapolation of prevalence and behavioural data can be done when the country's surveillance system is classified as "nationally acceptable," through:

- Paring the surveillance sites with non-surveillance sites by groups, by socioeconomic variables, including GDP per capita, adult male and female.
- Comparing the case-based surveillance results between surveillance sites and non-surveillance sites, the number of cases per 100,000 general population.
- Comparing HIV testing results, i.e., HIV prevalence by population groups between surveillance sites and non-surveillance sites.
- Proportionating/weighing the urban and rural populations by age groups.

A simple calculation of mean or median HIV prevalence from surveillance sites to represent the entire country can be misleading, and is not recommended. When a mean or median prevalence is calculated, its geographic coverage should be clearly stated. There is no

globally agreed approach to extrapolating from the sites to the national figures. In countries where a large heterogeneity in the HIV epidemic exists and program focuses only on those high burden areas, such an extrapolation may not be appropriate. Innovative approaches are encouraged.

Decision for funding. Certain surveillance options depend on the existing surveillance systems, technical capacity and available funding. The surveillance system should be developed with the country's data needs in mind. Countries are encouraged to develop a multi-year plan that incorporates key data needs and existing partner support. Unsustainable (one-off) surveys to meet donor needs may be deemed ethically unacceptable if they are not attached directly to programmatic interventions for the surveyed population.

- Case-based surveillance should be routinely implemented, with links to patient monitoring, follow-up care and treatment programs.
- HIV sentinel surveillance should be the first choice for key populations whenever HIV prevalence data are required.
- Wherever HIV sentinel surveillance exists, HIV sentinel surveillance plus should be considered to annually collect both prevalence and basic behavioural data.
- IBBS should be planned and implemented at an interval of three years only when:
 - There have been historical IBBS data points unless there is compelling evidence that something new will be detected with IBBS.
 - Adequate technical and implementation capacity locally.
 - Establishment and maintenance of sentinel surveillance system is not possible, such as in operationally challenging environment.
 - There is adequate allocated funding.

An optimal HIV surveillance system should have a case-based surveillance system that is evaluated regularly, plus either of the following depending on the funding situation,

- HIV sentinel surveillance or HIV sentinel surveillance plus of the most important populations in every major epidemic area and a few minor ones.
- IBBS in rationally selected sites that may be extrapolated to broader areas of the country.

For regional grants, an IBBS is not recommended in general. Data from country specific IBBS or sentinel surveillance and/or programmatic data in relevant countries should be analyzed to monitor the epidemic trend. In case the service delivery accounts for vast majority of the grants, grant specific surveillance sites may be included with consideration of flexibility to integrate into respective national surveillance systems.

Funding decisions for HIV surveillance activities should be made in the country and/or regional context. In the meantime, programmatic results, especially testing results, should be analyzed to track the trend of the epidemic. When using the programmatic data for the

purpose of tracking HIV epidemic, basic demographic and behavioural information should be collected for analysis.

Indicative Budget Level

Surveillance activities	Frequency	Suggested budget source	Indicative budget level (US\$)	Possible TA
IBBS	Every 3 years	Grants unless it is funded domestically or by partners	50-100k per group, each group with 3-5 sites	Required, 50-100K
Sentinel surveillance	Annual	Domestic*	1,000 per site	N/A
Sentinel surveillance plus	Annual	Domestic*	1,500 per site	N/A
HIV case-based surveillance	On-going	Domestic	N/A	Required, 50-100K
Population size estimation	Every 3 years	Grants unless it is funded domestically or by partners	100K per group with national coverage if not embedded in the IBBS, such as programmatic mapping	Required, 50-100K

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