

UNAIDS/WHO Working Group  
on Global HIV/AIDS and STI Surveillance

The pre-surveillance assessment  
Guidelines for planning serosurveillance of HIV,  
prevalence of sexually transmitted infections  
and the behavioural components  
of second generation surveillance of HIV



Joint United Nations Programme on HIV/AIDS  
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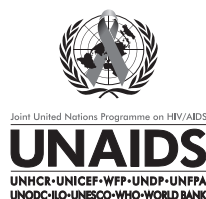
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## PREFACE

Global surveillance of HIV/AIDS and sexually transmitted infections (STIs) is a joint effort of the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) with other international institutions and partners. This guide is part of a series of technical resources on second generation surveillance that started with the *Guidelines for second generation HIV surveillance* published by UNAIDS and WHO in 2000 and aims to address specific technical issues related to strengthening surveillance systems.

WHO and UNAIDS thank the many organizations and people who provided input and resources for this publication, including the UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance, particularly Jesus M. Garcia Calleja and Cyril Pervilhac for their valuable contributions, the United States Centers for Disease Control and Prevention, the Malawi Ministry of Health, Neelamanie Punchihewa, Zelee Hill and Nigoon Jitthai. This publication was developed based on the many lessons learned over several years by participating national and international surveillance partners in how to design and strengthen surveillance systems. We are grateful to them for documenting and sharing their experiences.

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# INTRODUCTION

## Why this publication?

Effective public health action for preventing and controlling HIV requires comprehensive and accurate understanding of how the virus is being spread. Data generated through the systematic, ongoing collection of behavioural and biological data by national HIV surveillance systems are required to understand the dynamics of the epidemic and to enable appropriate responses. However, the task of identifying which data are needed, among which subpopulations and in which geographical locations in a given country is not always obvious.

This publication provides an overview of pre-surveillance assessment designed to address the questions needed to plan for surveillance while taking into account local variation and the constantly changing nature of HIV epidemics. The publication focuses on periodic HIV serosurveys, sexually transmitted infection (STI) surveys and behavioural surveys. It does not consider other elements of second generation HIV surveillance, including HIV and AIDS case reporting, routine service statistics (such as those from centres for voluntary counselling and testing and for preventing mother-to-child transmission) or mortality data. A pre-surveillance assessment is needed for initial and subsequent rounds of HIV surveillance to ensure that data needs and data gaps are identified and addressed. The purpose of the surveillance system must be clear to everyone to help ensure that its output will meet the expectations of those involved in its implementation.

## UNAIDS/WHO classification

Increasingly in recent years, many countries have instituted behavioural and biological HIV surveillance. In some epidemic settings, surveillance has been more focused on the general population, whereas in others the focus has been more on subpopulations that are perceived as being most at risk, or most vulnerable, to HIV infection. The guidelines on second generation surveillance produced by the UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance in 2000 (1) have been instrumental in stimulating this process. Those guidelines lay out a framework that involves classifying epidemics by type (low-level, concentrated and generalized) and then selecting subpopulations for surveillance according to these types. Other resources are also available that provide guidance: initiating second generation surveillance (2), conducting surveillance among pregnant women (3), using surveillance data (4) and estimating the sizes of population groups with high-risk behaviour (vulnerable subpopulations) (5).

## “Looking before we leap”

This classification system has some limitations in conceptualizing the diversity of HIV epidemics, but it has been instrumental in motivating countries to collect more comprehensive surveillance data. Experience has also taught to “look before we leap”, as a critical step in correctly planning surveillance activities in the context of national surveillance. The subpopulations to be included in surveillance systems need to be considered carefully, and assumptions should be avoided about who is at risk and who is not. Our understanding about vulnerable subpopulations should be based not on predefined notions or anecdotes about high-risk groups but rather on careful assessment and definition leading to realistic judgements about the epidemiological importance of various subpopulations in fuelling the spread of HIV.

### Planning for surveillance is a cyclical process

Surveillance is a process that may need to undergo changes as an epidemic progresses. Some countries are in the early stages of planning for surveillance and others have long-established systems. However, no country has such a static epidemic that reconsidering and adjusting to the changing nature of the epidemic is not required. Although the primary aim of surveillance is to measure trends, surveillance systems risk becoming stagnant if they are no longer producing the information a country needs. Planning for surveillance should therefore be a cyclical process in which data needs and data gaps are assessed on an ongoing, regular basis.

*The overall purpose of the seroprevalence, STI and behavioural components of HIV surveillance should be to provide information about the current epidemic and the potential for its spread and generating evidence for setting priorities among interventions and evaluating their total impact.*

Surveillance should be thought of as more than just a series of repeated behavioural and biological surveys. It should be thought of as a system for monitoring trends in the prevalence of HIV infection and risk behaviour over time in subpopulations that influence the spread of HIV infection, in addition to morbidity and mortality from HIV.

# THE SURVEILLANCE CYCLE

## Part 1: the pre-surveillance process

### What is the pre-surveillance process and why is it needed?

National HIV surveillance is a cyclical process (Fig. 1) that should always include a planning component involving the major surveillance partners before each round of surveillance (2). The process should ideally include the steps outlined below. These steps may not all occur in the order listed here, and in many countries they may not be done in a coordinated fashion. However, taking these steps into account can help countries achieve more complete coverage in a more comprehensive fashion.

Each of the steps of the pre-surveillance process below is described more fully in the text of this module. Since many partners play different roles in planning and implementing surveillance, establishing a coordinating body is important (see the first point below).

Countries whose surveillance systems do not monitor relevant and appropriately defined subpopulations are at risk of failing to detect emerging epidemics in time to do anything about them. Further, countries with advanced epidemics are at risk of not improving if they fail to realistically assess the source of new infections and take steps to target intervention efforts where they will make the most difference. It is therefore worth taking the extra time and effort to go through the pre-surveillance process to plan appropriately and avoid making mistakes that will ultimately cost time, money – and potentially lives.

### Steps in the pre-surveillance process

- *Identify a coordinating or decision-making body.* This body should serve to help the government and other surveillance partners and stakeholders agree on the purpose of surveillance and set priorities for the most urgent data needs in an environment of sometimes competing priorities. It should ideally be convened by the health ministry or national AIDS control programme and meet regularly.
- *Agree on the purpose of surveillance.* The first task of the coordinating body is to agree on the purpose of surveillance. In a nutshell, surveillance should help to provide an understanding of how HIV is spreading by identifying the source of new infections and how the pattern is changing over time. It should also help in setting priorities among interventions and in evaluating the national effort to reduce HIV transmission.
- *Establish criteria for selecting subpopulations and geographical coverage areas for surveillance.* The coordinating body should be responsible for selecting the subpopulations and geographical areas to include in the surveillance system. Subpopulations and geographical areas should be carefully selected based on a set of established criteria that are driven by a solid understanding of the dynamics of the epidemic in the country and the corresponding data needs.
- *Gather information to 1) decide which subpopulations and geographical areas to include in surveillance and 2) to guide survey implementation.*

*Assess what is currently known about the national epidemic or subepidemics.* This step involves reviewing existing data and information about HIV and STI trends and HIV-related risk behaviour to identify potential hotspots and at-risk or vulnerable subpopulations, including youth. Hotspots are geographical areas with higher-than-average numbers of HIV-infected people or people engaging

in high-risk behaviour. Information sources include published and unpublished literature and reports, mass media and people who are knowledgeable about the local epidemic situation.

*Conduct pre-surveillance assessment using qualitative assessment methods.* This step involves fieldwork to further identify and verify geographical hotspots and to gather information to help 1) clearly define subpopulations to be included in surveillance and 2) guide surveillance fieldwork.

*Gather information on risk behaviour and HIV levels in the general population through general population surveys.* In addition to providing important information about risk in the general population, these surveys can also be used to provide information to help validate whether supposedly high-risk subpopulations are really at higher risk than the general population.

- *Finalize subpopulation and geographical selection.* This selection should be based on the criteria that have been established and the information gathered during the pre-surveillance activity phase.

## Part 2: conduct surveillance

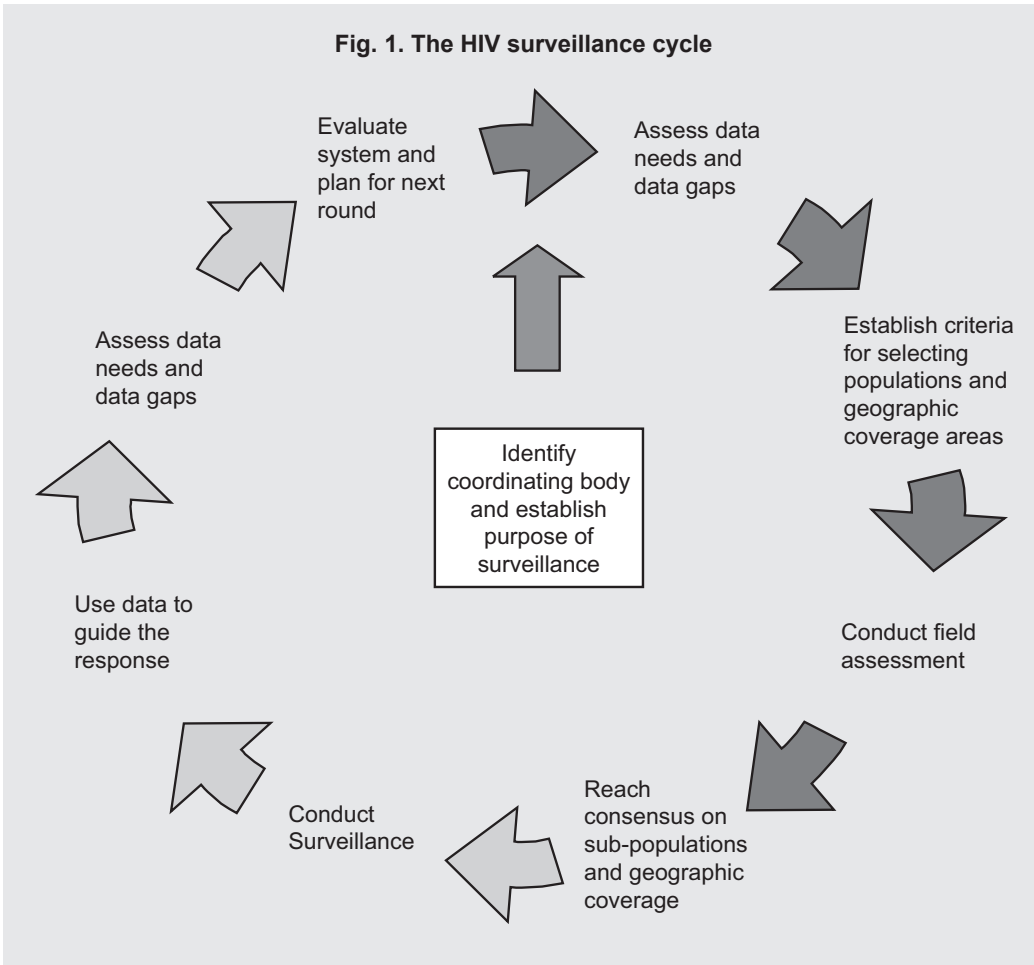
Ideally, surveillance data should not begin to be collected until after the procedures outlined in the pre-surveillance process above are followed. Procedures for conducting surveillance are not presented in this module but can be found elsewhere (1–3,6,7).

## Part 3: use data from the surveillance system to guide the response

Surveillance data should be used to target and advocate for resources and interventions and, over time, to evaluate the impact of the sum total of interventions in the country. Procedures for using data are not presented in this module but can be found elsewhere (4,8,9).

## Part 4: plan for the next round of surveillance

Although surveillance refers to repeated cross-sectional surveys of comparable subpopulations over time, a critical part of the surveillance cycle is to reassess and adjust the surveillance system based on the information generated by previous rounds and also on the changing dynamics of the epidemic. It is also critical to monitor the implementation and evaluate the efficacy of the surveillance system itself.



## PLANNING FOR SURVEILLANCE

Before data begin to be collected for surveillance, a blueprint or protocol is needed that will guide the data collection process. Developing the protocol is much easier after going through the steps in the pre-surveillance process and increases the likelihood that the protocol will address the agreed-on goals and purpose of the surveillance system. Other publications (1,2,3,8,10) describe some of the steps in the pre-surveillance process, but this publication provides additional detail and reflects additional experience gained in the past several years of implementing surveillance.

Planning for surveillance is an iterative, nonlinear process, and information that becomes available during the process may alter decisions made earlier. This does not mean that the decisions made were incorrect. On the contrary, the initial round(s) of surveillance often provide the impetus for changing the system.

Surveillance systems can be greatly improved as understanding of local epidemic dynamics increases. It may take more than one round of surveillance to gain the trust of surveillance partners and to ensure good cooperation and valid data. In some cases, multiple rounds are needed to get a clearer picture of which subpopulations are at risk and whether these subpopulations have more subsets with more risky behaviour. For example, in some countries surveillance data have shown that some subcategories of men who have sex with men have more frequent exposure to HIV than others or that subpopulations assumed to be at high risk turn out not to be, such as certain migrant subpopulations. Such a discovery can lead to more in-depth investigation of which migrant subpopulations are truly at risk. Nevertheless, more than one round of surveillance may be needed to verify the situation. A surveillance system that remains flexible and that can adapt to change or updated information is in a better position to improve the response to the epidemic than one that remains completely static.

The steps outlined in Box 1 reflect a summary of the components that are necessary for planning surveillance systems. Many important steps need to be completed before the survey protocol can be developed. This process can be time-consuming and frustrating, especially during the first round of surveillance. Those managing the process would do well to plan realistically for the time and resources consumed by this preparatory phase.

**Box 1. Steps in the surveillance cycle: a summary**

Step 1: Identify a coordinating body

Step 2: Assess data needs and gaps and agree on the purpose of surveillance

Step 3: Establish criteria for selecting subpopulations and geographical coverage areas

Step 4: Conduct field assessment: gather information to help with decisions about subpopulations and geographical coverage areas and to guide survey implementation

- Assess what is currently known about the national epidemic
- Conduct field assessment or preliminary mapping to gather information about potential hotspots and at-risk subpopulations, including:
  - how to define them
  - how and where to access them
  - whether they engage in risk behaviour
  - how many there are (estimated subpopulation size)
  - where people seek care for STIs.

Step 5: Reach consensus on subpopulations and geographical coverage

- Develop clear operational definitions and inclusion criteria

Step 6: Conduct surveillance (main survey)

- Develop a sampling design
- Finalize the survey protocol
- Develop a sampling frame (as the first step of survey implementation)
- Prepare fieldwork
- Collect data
- Analyse data

Step 7: Use data to guide the response

Step 8: Assess data needs and gaps

Step 9: Evaluate the system and plan for the next round of surveillance

- How a subpopulation for surveillance will be defined (criteria for being considered a member of the respondent group)
- Where the subpopulation will be accessed
- How the subpopulation will be accessed
- Whether the subpopulation members will consent to participate in the survey and under what conditions
- Whether enough of the subpopulation exists to warrant being a surveillance subpopulation
- Whether the subpopulation actually engages in risk behaviour
- The degree to which the subpopulation moves around
- The degree of inward and outward migration and/or duration of being a member of the subpopulation

## STEP 1: IDENTIFY A COORDINATING BODY

The purpose of the surveillance coordinating body is to provide guidance to and serve as an overall decision-making committee for the surveillance system. The coordinating committee acts similarly to the board of directors of a company. It is responsible for high-level decisions such as defining the purpose of surveillance in the country, deciding which data to collect and ensuring widespread use of the data; however, it does not necessarily get directly involved in day-to-day implementation activities. The coordinating committee makes certain that the surveillance system is set up to meet the data needs of the country and that it is adequately funded. It also facilitates coordination between surveillance partners, monitors the progress of the surveillance process and ensures that the findings and recommendations are disseminated so that they can be acted on.

Surveillance is usually the responsibility of a surveillance unit in the health ministry or within the national AIDS control programme. Many countries also have either a well-defined or loosely structured coordinating body that makes surveillance decisions. In some countries, this group is called the surveillance advisory committee or working group. In other countries, a working group on monitoring and evaluation or a committee on surveillance and research addresses surveillance issues. Whichever the case, having a surveillance advisory committee is one way to help ensure that the surveillance agenda stays on track.

There is no uniform formula for who should be on the coordinating body. Ideally, the composition of this group should reflect the various national and international bodies whose interests will be served by the surveillance system. However, many countries already have several surveillance coordinating bodies that have different responsibilities. Merging these groups into one umbrella committee should be worked towards to help facilitate coordinated surveillance decisions, but it should not negate the work of the functioning structures already in place.

The committee must be sufficiently empowered with a range of members, including those able to make final decisions and leverage funding and human resources, researchers who can advise on survey implementation, policy-makers and other stakeholders. Ideally, the surveillance coordinating committee is headed by the health ministry or the national AIDS control programme and has on it representatives from other relevant government ministries such as the education and defence ministries, the public or private research agency implementing data collection, technical advisers from national and international agencies such as UNAIDS and WHO, highly involved nongovernmental organizations and key donors. Having the national research council (or similar body) on the committee may also be useful because of their awareness of other ongoing or planned research that could be coordinated with the surveillance system and potentially avoid duplicative data collection.

Other important stakeholders should be involved in the surveillance process, such as members of the subpopulations from whom data will be gathered and gatekeepers to these groups. In some instances, these stakeholders could be on the surveillance coordinating committee, such as a representative from a national nongovernmental organization of sex workers or a member of a trade union for truck drivers. Although these stakeholders are numerous and are usually located at the province or district level, involving them is important. Without strong partnerships, decisions made by the surveillance coordinating group can be divisive and, at times, erroneous. This is why involving the various partners at every step from planning through dissemination is critical. Consider what would happen if the coordinating committee chose to include brothel-based sex workers as the surveillance subpopulation without consulting a local women's nongovernmental organization that advocates for better health services for sex workers. The coordinating committee would risk losing the invaluable

access to and information about the subpopulation the nongovernmental organization would provide. The nongovernmental organization might not see the surveillance data as a source of information that could help in advocating for increased services but may instead consider surveillance yet another fruitless, and invasive, research exercise.

The decision about whom to include on the coordinating committee will be specific to each country's needs and experience. However, even if they are not directly represented on the coordinating group, subpopulation group members and other stakeholders need to be involved throughout the surveillance process (Box 2).

**Box 2. Example of the responsibilities of a surveillance coordinating committee**

- Define the purpose of surveillance
- Identify data gaps and data needs
- Identify and select activities and surveys that will be part of the national surveillance system (including ad hoc surveys conducted by various donors)
- Identify funding sources
- Advocate to policy-makers and stakeholders about the importance of surveillance
- Facilitate coordination of activities among existing surveillance partners
- Make final decisions about subpopulation selection and geographical coverage
- Ensure the quality of the overall system
- Maintain the institutional memory of surveillance activities, including databases
- Provide input into data interpretation and conclusions drawn
- Maximize the dissemination and use of data
- Ensure that ethical issues are considered
- Provide technical input in surveillance protocols

## STEP 2: ASSESS DATA NEEDS AND DATA GAPS AND AGREE ON THE PURPOSE OF SURVEILLANCE

Although agreeing on the purpose of surveillance seems like a straightforward process, the task is often complicated by competing priorities and lack of clarity on how the data will be used. Increasingly, the purpose of surveillance is also complicated by ethical issues and confusion over the distinctions between unlinked, anonymous testing for surveillance purposes on the one hand, and case-finding, voluntary counselling and testing and services for preventing mother-to-child transmission on the other (8).

### The multiple objectives of surveillance

In general, the purpose of HIV surveillance systems is to improve the response to the epidemic by:

- helping to provide an understanding of how HIV is spreading, including the source of new infections and how this is changing over time;
- helping to set priorities among the needs for interventions in terms of vulnerable subpopulations and geographical locations;
- providing information to advocate for resources and interventions;
- providing data to monitor and evaluate the impact of the national prevention and care response; and
- monitoring STIs that can serve as an early warning system.

*However, the overall purpose of surveillance remains the same, regardless of the specific epidemic state: to improve the response to the epidemic.*

These objectives can be addressed in many ways. Depending on the epidemic setting or who is supporting and implementing surveillance, some objectives are given higher priority than others. For example, in low-level epidemics, surveillance tends to be most useful for providing a window on the potential for an epidemic to emerge. In concentrated epidemics, the predominant role of surveillance tends to be guiding focused intervention efforts among subpopulations at the highest risk of HIV and projecting the likely future course of the epidemic to better target prevention efforts. In high-prevalence settings, more emphasis tends to be placed on using surveillance to evaluate the success of the response and to plan for care and support.

### Who makes decisions about the design of the surveillance system and what goes into the decision-making process?

Some of the critical decisions to be made during the initial design phase relate to:

- what to measure: which behavioural and biological indicators to use;
- who to measure: which subpopulations to include and how to define them;
- where to measure: which areas of geographical coverage to include;

- how often to measure: frequency of data collection;
- how to measure;
- feasibility;
- costs of the system; and
- how data should be collected.

Answers to these questions should relate directly to the purpose of surveillance and how the data will be used. Careful planning can help eliminate situations in which the surveillance design responds to some needs and not others.

For example, data measured at the national level may respond to the need to evaluate the impact of the national programme and perhaps report indicators at the global level. However, these data might not respond to the need to understand differences in how the epidemic is progressing or interventions are working in different geographical areas of a country. This problem can be addressed by treating the various geographical areas of a country as separate strata for which separate measures can be obtained with adequate precision. The results from different strata can then be aggregated to provide overall summary measures if desired. These summary measures may or may not be nationally representative depending on how the sampling was done. In any case, forethought and careful planning are required at the design stage.

There are many potential conflicts of interest when designing surveillance systems, partly because there are many different stakeholders. Examples include the following.

- A national programme may want data at the national level to evaluate their programme, but one overall figure at the national level may mask what is happening in different regions of the country.
- Implementers of a large-scale programme may want data to evaluate the impact of their programme. But providing surveillance resources solely in regions or among the subpopulations with large-scale programmes can leave a country with great data gaps. For example, a country may fail to collect data in vulnerable areas where there are no programmes in place, leading to situations in which emerging subepidemics may not be detected until it is too late.
- Governments may want to detect who is infected with HIV and therefore test only people with symptoms of HIV or presumed high-risk behaviour (such as people with STIs), leaving the country without any objective measures of prevalence in subpopulations with different levels of risk.
- Researchers may want to establish the risk factors that are associated with the transmission of HIV in different settings or measure the effectiveness of specific interventions, so they may promote or support surveillance systems designed primarily to meet those objectives.
- Nongovernmental organizations or implementing agencies may want surveillance data to advocate or lobby for programming in the subpopulations with whom they work.

Any one of these situations can leave a country with great data gaps if some needs are erroneously given priority over others. Having a coordinating body, such as the surveillance advisory committee described in the preceding section, is therefore helpful to ensure that the design of the surveillance system meets the country's data needs while also meeting the needs of the different surveillance partners and stakeholders.

## What type of surveillance will achieve the multiple objectives described above?

### Which components of surveillance need to be included?

Meeting the objectives outlined above requires having surveillance data and analysing them in a way that:

- improves understanding of the dynamics of the epidemic, including behavioural links among subepidemics or subpopulations and how they contribute to the potential for epidemic spread;
- obtains locally relevant information on the source of new infections over time;
- evaluates the impact of prevention programmes by understanding how programmes affect changes in behaviour over time and how changes in behaviour affect HIV and STI transmission over time; and
- improves the response by focusing interventions in a way that prevents the most new infections.

To do this, trend data are needed on:

- the prevalence of HIV infection in subpopulations at risk of contracting or transmitting the virus, including the general population;
- the magnitude of STIs that enhance the transmission of HIV or are “markers” of high-risk behaviour in the general population and among vulnerable groups; and
- behaviour that exposes people to HIV, including links between subpopulations with different levels of risk (such as the proportion of men having unprotected sex with both sex workers and regular partners, the proportion of men and women having unprotected sex with multiple partners, the proportion of older men having sex with younger women, the proportion of injecting drug users having sex with sex workers or the proportion of men who have sex with men who also have sex with women).

Surveillance systems for collecting these types of data are frequently referred to as 1) HIV surveillance systems, 2) STI surveillance systems and 3) behavioural surveillance systems. Although there are many other important data sources, these three are the focus of the current guideline and are key to inform prevention programming. Additional systems that collect information on morbidity and mortality (such as AIDS case reporting and vital registration and mortality data) will additionally inform care and support programmes.

These three types of data are needed for both the general population and for defined subpopulations with different levels of risk behaviour. They may either be collected from the same individuals at the same time or at different points in time from similar subpopulations. But collecting these three types of data over time among defined subpopulations in defined geographical areas makes available much of the information needed to address all four surveillance objectives outlined above.

## What surveillance data can do

### Provide an understanding of how HIV is spreading

In lower-prevalence settings, determining how the epidemic is likely to unfold and how it is likely to affect different segments of the population requires knowing how HIV trends are evolving in vulnerable groups over time and how these groups interact with each other

and with subpopulations with lower levels of risk behaviour. The prevalence of STIs, which serve as co-factors for transmission, also needs to be known. This information can be used to project how changes in behaviour or STIs will affect the overall epidemic. Most importantly, it shows the sources of the greatest number of new infections (in terms of subpopulations and geographical locations) and how these are shifting over time. This information, which can be made available through integrated analysis of surveillance data, is a powerful tool for responding to the epidemic (9). Surveillance systems also frequently contribute important information for estimating the number of people living with HIV/AIDS as well as the size of vulnerable groups in a country, projecting where the epidemic may be progressing and identifying population groups that may be at elevated risk for HIV transmission.

Although this paradigm may seem most relevant for low-level and concentrated epidemics, even in most high-prevalence settings not everyone is at equal risk of infection. Further, although tracking changes in HIV and risk behaviour in the general population is of major importance, identifying different patterns of risk behaviour in different subsets of the population is still important so that the source of new infections can be understood and responded to appropriately. In addition, surveillance can provide information about the geographical spread in different areas of the country and according to urban versus rural status.

### **Setting priorities among interventions**

If where and among whom HIV is spreading and how it is shifting over time are known, then the priorities for the response can be set accordingly. If the prevalence of specific STIs is known, including ulcerative diseases, then efforts to control these co-factors for HIV transmission and acquisition can be given appropriate priority.

### **Providing information for advocacy**

Demonstrating how the number of HIV infections is likely to increase over time, especially if nothing is done to stop this, provides a more effective case for an aggressive response. Similarly, demonstrating how a strong response leads to declines in the number of new HIV infections allows advocating for continued prevention efforts.

### **Contributing to monitoring and evaluating programme impact**

Behavioural and biological prevalence trends are mutually linked over time because changes in behaviour ultimately lead to changes in the rate of transmission of new infections. If behavioural and biological data are available from the same (or similar) subpopulations over time, and a strong and effective intervention response can be documented in these subpopulations with high enough coverage to make a difference, then plausible evidence can be presented that behaviour change eventually led to the observed changes in the prevalence of STIs and HIV. In this way, surveillance data can be used to evaluate the impact of national programmes. However caution should be applied when interpreting the results; both behaviour and STI prevalence take some time to show changing trends, and changes in HIV prevalence take somewhat longer.

## What surveillance data cannot do

### Surveillance data cannot establish the cause of HIV transmission

The purpose of surveillance is not to establish the cause of HIV, which has already been done in numerous studies. What is needed from surveillance data is information on the levels of HIV, the levels of high-risk behaviour exposing people to HIV transmission and the levels of STIs over time in populations with an identifiable risk of HIV, including the general population, especially in high-prevalence settings. Information is also needed on behavioural links between subsets of the population with higher and lower levels of risk behaviour to assess the potential for dissemination of HIV. If this information is available, then the surveillance objectives can be addressed, even if behavioural and biological data are not available from the same individuals at the same time.

### Surveillance data cannot correlate biological and behavioural indicators at one time

Surveillance data is often expected to be able to link behavioural and biological indicators. They can if these indicators are analysed in relation to one another over time. However, establishing the link between behaviour and HIV or STI status is more difficult when both the behavioural and biological measures are taken at the same time in the same individuals. This is because of the long duration of HIV infection (as well as some other STIs) and the fact that a person's behaviour may change significantly over the life of his or her infection. Recent behaviour in an individual does not necessarily predict his or her HIV status or even STI status. Likewise, for treatable STIs, current infection status does not necessarily represent incidence of infection (that is, the likelihood that the person has been infected with an STI during the period corresponding to that for which the risk behaviour was measured). So a person's recent behaviour may not be linked to his or her current STI status. Similarly, linked data are of limited value as a foolproof method for validating reported low-risk behaviour.

## Should behavioural and biological indicators be collected from the same individuals at the same time?

There are certain advantages to collecting behavioural and biological data together. Besides conducting only one survey instead of multiple surveys being more convenient, combined behavioural and biological surveillance can enable 1) identifying correlates of HIV infection and 2) obtaining proxies for incidence by measuring the prevalence among people who have only recently become part of the vulnerable subpopulation (such as people 15–24 years old who started their sexual activity relatively recently, sex workers or injecting drug users of short duration). Recent technological advances have made the direct measurement of HIV incidence from blood samples increasingly possible.

These are the factors that make the relationships between behaviour and biological factors difficult to interpret in cross-sectional studies. Even when time trend data are available, they must be interpreted cautiously because groups at high risk of HIV infection are notoriously mobile, making inward and outward migration an important factor influencing behavioural or biological trends.

## So how can one determine when to collect what?

### UNAIDS/WHO recommendations for surveillance in different epidemic settings

In 2000, UNAIDS and WHO (1) laid out a framework for surveillance in low-level, concentrated and generalized epidemics and updated this in later publications (3). Table 1 lists the *core* surveillance recommendations, but the guidelines are quite flexible in terms of additional surveillance studies for countries that have the resources to do more.

**Table 1. Recommendations for core surveillance in different epidemic settings**

	HIV surveillance	STI surveillance	Behavioural surveillance
<b>Low level</b>	<ul style="list-style-type: none"> <li>• HIV serosurveillance in groups considered to engage in high-risk behaviour</li> <li>• Analysis of available data on blood donor screening</li> </ul>	<ul style="list-style-type: none"> <li>• Analysis of available STI surveillance data</li> </ul>	<ul style="list-style-type: none"> <li>• Risk behaviour surveys in groups considered to engage in high-risk behaviour</li> </ul>
<b>Concentrated</b>	<ul style="list-style-type: none"> <li>• HIV serosurveillance in groups considered to engage in high-risk behaviour</li> <li>• Annual HIV serosurveillance in pregnant women in a limited number of urban areas and in bridging subpopulations</li> <li>• Analysis of available data on blood donor screening</li> </ul>	<ul style="list-style-type: none"> <li>• Analysis of STI data in groups considered to engage in high-risk behaviour and bridging subpopulations</li> </ul>	<ul style="list-style-type: none"> <li>• Repeated surveys in groups considered to engage in high-risk behaviour, in bridging subpopulations and in the general population in urban and high-exposure areas</li> </ul>
<b>Generalized</b>	<ul style="list-style-type: none"> <li>• Annual HIV serosurveillance among pregnant women in urban and rural areas</li> <li>• Increase sample size in high-volume sites to allow for analysis by age groups</li> </ul>	<ul style="list-style-type: none"> <li>• Analysis of STI surveillance data in groups considered to engage in high-risk behaviour for HIV infection</li> <li>• Analysis of STI surveillance data in the general population</li> </ul>	<ul style="list-style-type: none"> <li>• Repeated behavioural surveys in groups considered to engage in high-risk behaviour for HIV infection</li> <li>• Repeated risk behaviour surveys in the general population with a focus on young people</li> </ul>

<sup>a</sup> For more information on core and additional surveillance components, see *Second generation surveillance for HIV: the next decade* (1) and *Guidelines for conducting HIV sentinel serosurveys among pregnant women and other groups* (3).

These guidelines have been extremely useful in helping countries focus their surveillance resources. Countries have made great strides in meeting the core surveillance requirements, and many countries have gone beyond the minimum recommendations, although maintaining consistent standards of quality remains a challenge.

Deciding which surveillance data to collect on which subpopulations in which geographical areas is one of the biggest challenges countries face in their surveillance systems. Failure to make deliberate, well-thought-out choices can have the unfortunate consequence of leaving countries without adequate information to respond effectively to the epidemic.

So what is the basis for deciding what data to collect when? How should the decision be made whether to conduct behavioural surveillance, biological surveillance or both? With what frequency should each be done? There are no hard and fast rules. It depends on several factors related to the subpopulations of interest, and no two countries are alike.

Major factors to consider when selecting subpopulations for surveillance and determining which data to collect are:

- the prevalence of HIV in the subpopulation to be surveyed;
- the amount of inward and outward migration in the subpopulation to be surveyed;
- the amount of exposure to HIV (level of risk behaviour) in the subpopulation to be surveyed;
- the existence and intensity of interventions targeted at the subpopulation to be surveyed;
- available resources (both human and financial) to conduct surveillance surveys;
- care-seeking behaviour for perceived STI;
- the current status and feasibility of antenatal screening for syphilis; and
- the national strategic plan for combating HIV/AIDS.

## HIV and behavioural surveillance

**Prevalence of HIV.** In general, once the prevalence of HIV in a population reaches a high level (such as 20% or more), it is likely to stay high in most populations, even when effective interventions are in place. This is because, once people are infected with HIV, they stay infected for life, and unless they leave (migrate out of the population being surveyed) or die, they will continue to contribute to the HIV prevalence in that population. In contrast, in populations with high turnover (such as sex workers in most countries) prevalence levels can change more rapidly. Overall, having data on a regular basis (every 1–2 years) is helpful. This is because of a) the need to keep the focus on populations affected by HIV, b) the possibility of anomalous data in any given year, c) the mobility of many populations affected by HIV and d) the need for data to document evidence of increasing or decreasing HIV incidence. A word of caution – given the multiple biases that can affect HIV trend data, they must always be interpreted very carefully. Shifting patterns of selection bias and inward and outward migration are especially tricky to deal with and can lead to serious misinterpretation of trends if the analysis does not appropriately account for these factors. Steps to guard against this such as carefully defining the group being surveyed are critically important.

In populations with a low prevalence of HIV but a high prevalence of risk behaviour, HIV surveillance every 1–2 years is especially important because HIV can increase rapidly once it enters the population.

Less frequent surveillance is only justifiable when both HIV prevalence and risk behaviour are low. However, conducting surveillance less than once every two years should be avoided because of the risk of missing changing patterns in the population.

**Inward and outward migration.** If there is substantial inward or outward migration (high turnover) in the population being surveyed, then measuring both HIV and risk behaviour more frequently is important. In such situations, interpreting trends is tricky and should be interpreted in light of the inward and outward migration patterns. Inward and outward migration can happen for a variety of reasons and affect surveillance trends in different ways.

The following are examples of inward and outward migration among female sex workers.

- New women enter sex work.
- Existing sex workers leave the profession.
- HIV-infected sex workers become too ill to work.
- HIV-infected sex workers are forcibly removed from brothels.
- HIV-infected sex workers die.
- Brothel-based sex workers begin working via mobile telephone or Internet (outward migration from brothel-based sex work, inward migration to mobile phone sex work).
- Law enforcement officials conduct a raid or crackdown on sex workers and many of them are arrested and put in prison.
- Sex workers who do not wish to participate in surveillance surveys hide or stay away when surveillance is being done.
- Sex workers who are reached by interventions participate in surveillance at increasingly higher rates each year (a type of differential inward migration that can occur especially when implementing agencies are involved in surveillance).
- Sex workers move from one city to another.

These are just some of the ways in which inward and outward migration patterns can affect HIV behavioural or biological trends, thereby necessitating surveillance at regular intervals of 1–2 years.

***Amount of exposure to HIV.*** If a population is exposed to HIV through high levels of risk behaviour, such as having unprotected sex with multiple partners, including sex workers, and sharing injecting equipment, then more frequent behavioural surveillance is required. This requirement exists whether the prevalence of HIV is high or low. Either way, risk behaviour needs to be reduced, either to prevent a potential epidemic or diminish an already existing epidemic. If a population is surveyed and has low levels of risk behaviour, then this group may not be a priority for surveillance at the time. However, the situation should be re-evaluated for subsequent rounds of surveillance so that emerging groups with high levels of risk behaviour are not overlooked.

***Existence and intensity of intervention.*** If a population has a high prevalence of HIV and/or high levels of risk behaviour, they should be given priority for intervention. If there is no intervention in place, then continued surveillance becomes problematic.

***Available resources.*** In a very real sense, the criterion of available resources overrides all the others because quantity at the expense of quality does not necessarily represent a net gain despite the importance of good surveillance coverage (adequate number of groups and locations).

## STI surveillance

Periodic surveys (such as every 2–3 years) of the prevalence of STIs, the causation of STI-related syndromes and antimicrobial susceptibility of bacterial STIs are important because of the role of STIs in enhancing the transmission of HIV and the need to ensure that symptomatic STI syndromes as well as asymptomatic STIs are being managed with effective antibiotics and antiviral agents (such as acyclovir) where needed. Having data on STIs available is important to act as an early warning of the potential for HIV exposure. Repeated cross-sectional STI surveys can also be a powerful tool for monitoring the effects of HIV and STI programmes because they can demonstrate the combined effects of changes in risk

behaviour, changes in health-seeking behaviour and improved quality of care while adapting to changing patterns of causation and antimicrobial susceptibility. Routine case (syndromic or causation-based) reporting may add value to the surveillance for STI and its trends (7).

## Integrated biobehavioural surveys

If resources are available to measure HIV, STIs and behaviour regularly, this can and should be done. However, if resources are stretched, a phased approach to surveillance may be considered in which behavioural indicators (which are somewhat easier and less costly and invasive to obtain) can be measured more frequently, and biological indicators of HIV and/or STIs can be measured more intermittently. One thing to bear in mind is that STIs are especially influential in populations with a low prevalence of HIV infection. In these situations, STIs can greatly accelerate the spread of HIV. As the prevalence of HIV rises, the proportion of HIV infections that are attributable to the presence of an STI is relatively less, especially for bacterial (curable) STIs (11). Giving priority to STI surveillance in settings with a lower HIV prevalence therefore makes sense. However, if low levels of STIs are documented in a baseline survey (such as less than 3% prevalence of bacterial STIs such as gonorrhoea, chlamydia or syphilis) then repeated measurements in the future are unlikely to be very valuable because registering any significant changes requires very large sample sizes.

A special case of integrated biobehavioural surveys is the national surveys that measure HIV prevalence, since these surveys also measure behaviour and some also include STIs. These are recommended to be conducted in generalized epidemics with high prevalence levels (13).

## STEP 3: ESTABLISH CRITERIA FOR SELECTING SURVEILLANCE SUBPOPULATIONS AND GEOGRAPHICAL COVERAGE AREAS

Selecting subpopulations for inclusion in surveillance should be driven largely by epidemiological factors, similar to decisions about who should be targeted for intervention. This section discusses the epidemiological foundations for selecting subpopulations, which have been laid out in many journal articles and guidelines. The section also addresses external influences that need to be managed, such as pressure from donors and policy-makers.

Similar to the other steps in the surveillance cycle, subpopulation selection is not an activity that happens only when surveillance is being initiated for the first time in a country. Many countries already have established surveillance systems. However, responding appropriately to changes in the epidemic or to new knowledge about risk groups requires continual assessment of data gaps and willingness to add and subtract surveillance subpopulations as needed. Factors that drive these types of changes may include improved capacity of the surveillance staff, changes in the availability of resources, emergence of new risk subpopulations or data being collected from a subpopulation and then no longer being considered useful.

In generalized epidemic settings, monitoring antenatal care attendees has been the cornerstone of surveillance. This group is convenient to sample and is routinely used as a proxy for the general population. However, they do not provide the kind of complete and accurate information required to understand the factors driving the spread of HIV over time. In part for this reason, conducting surveillance surveys on community-based samples of the subpopulations more likely to transmit or be infected by HIV can be very helpful in high-prevalence settings. For example, female sex workers and their clients play a major role in HIV transmission in many countries with generalized epidemics. In contrast, in countries with low-level and concentrated epidemics, although high-risk subpopulations are given priority for surveillance, information on these groups ultimately represents only isolated pieces of the overall puzzle, and obtaining a comprehensive picture of the potential for epidemic spread requires widening the scope of the surveillance system to include bridge subpopulations and the general population.

### Epidemiological criteria for selecting subpopulations

A solid understanding of the dynamics of an epidemic in a country and corresponding data needs should drive the selection of subpopulations for inclusion in national surveillance systems. The main purpose of surveillance is to provide an ongoing understanding of local epidemics so that an appropriate response can be planned and implemented. If the response is implemented as planned, then an important secondary role for surveillance is to track progress towards reaching the goals of the plan. If the response is inadequate, surveillance data can and should be used to draw attention to this.

The selection of groups should be driven by their usefulness in helping achieve these objectives. Specifically, subpopulations should be chosen to provide information about:

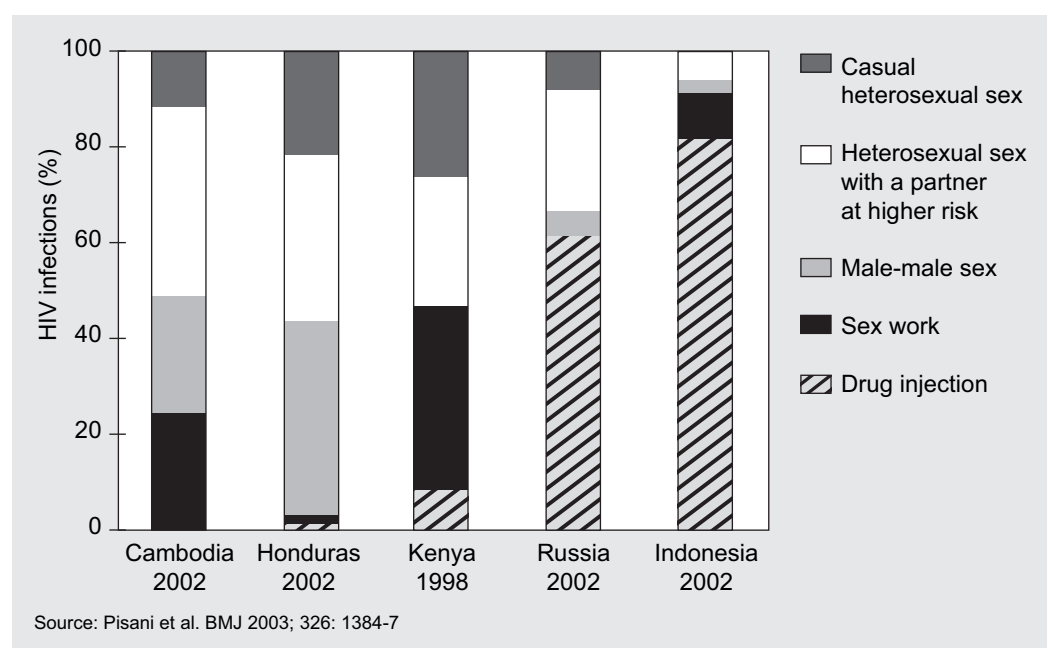
- where and among whom the epidemic is spreading;
- where and among whom the potential for future spread exists based on levels of STI or of behaviour that exposes people to HIV; and

- how behaviour is changing in response to intervention efforts and HIV prevalence levels as a result of changes in behaviour and STI levels.

In low-level and concentrated epidemic settings, these subpopulations may include sex workers and their clients, injecting drug users, men who have sex with men and other subpopulations with higher than average numbers of sexual partners. The last subpopulation varies by setting but may include such groups as mobile and migrant workers, members of the uniformed services and long-distance truck drivers. In settings with a very high prevalence of HIV in the general population (such as in many countries in Africa), segments of the population with more frequent high-risk behaviour exposing them to HIV infection must still be identified and targeted for intervention. Surveillance can play a role in helping identify these subpopulations and monitoring their behaviour. There are no firm rules about who these subpopulations are or whether they can be categorized as subpopulations. This is one reason why the pre-surveillance assessment is so important.

An important aspect of selecting subpopulations for HIV surveillance is knowing the source of new infections and how it is changing over time. Fig. 2 demonstrates how countries in the same category in terms of type of epidemic (that is, generalized, concentrated or low-level) can differ greatly in terms of the source of new infections. Cambodia, Honduras and Kenya are all classified as having generalized epidemics. But the source of the greatest number of new infections in Kenya (in 1998) was from sex workers, whereas in Cambodia (in 2002) it was the low-risk partners of people with high risk (mostly female partners of clients of sex workers) and in Honduras (in 2002) it was men who had sex with other men. The Russian Federation and Indonesia both have concentrated epidemics largely driven by infection among injecting drug users, but apparently with more sexual transmission in Indonesia at the stage these estimates were done (12). The challenge for surveillance, and ultimately for the efficient targeting of prevention and care efforts, is to identify which subpopulations are at higher risk of infection (both acquiring and transmitting) in each country. Accounting for local differences within a country would be important in this type of analysis, such as in urban and rural areas or in various hotspots.

**Fig. 2. Distribution of new HIV infections by type of exposure in selected countries, 1998–2002**



## Selecting subpopulations for surveillance

The following are key issues to consider when selecting subpopulations for surveillance.

- What are the population groups with high-risk behaviour?
- What is the health-seeking behaviour for STIs?
- For subpopulations other than the general population:
  - How large is the subpopulation?
  - Is the subpopulation accessible for surveillance?
  - How will surveillance in this subpopulation contribute to understanding the epidemic in the country?
  - What interventions have been implemented or are planned among this subpopulation?
  - Could conducting surveillance cause potential harm to this subpopulation?

## What is a population group with high-risk behaviour?

“Population groups with high-risk behaviour” as used in this publication refers to subsets of the general population whose behaviour puts them at higher risk both for becoming infected with HIV and for transmitting it to others. Sex workers and injecting drug users are among the population groups with highest risk because they very frequently engage in behaviour that can both expose them to HIV and also transmit it to others. Some men who have sex with men, especially those who sell or buy sex frequently or have anal sex with multiple partners, comprise a population group with high-risk behaviour.

Other subpopulations that may be at elevated risk for HIV transmission are sometimes defined by their occupation, age or migratory status. Population groups with high-risk behaviour commonly defined this way include police officers, military personnel, long-distance truck drivers, migrant workers, cross-border traders and youth out of school. Sometimes surveillance subpopulations are selected because they are the traditional groups that are assumed to engage in high-risk behaviour. Although there is a basis for considering some of these groups, the assumptions about their risk behaviour are frequently not realistic. After all, the behaviour in which these “groups” engage and not their occupations or age places them at risk.

These “traditional” population groups with high-risk behaviour often provide a starting-point for subpopulation selection in a country, but the important step of determining, for each country, whether these are the most important subpopulations to monitor is often skipped. Consider military personnel, a typical subpopulation selected for surveillance in many countries. Military groups are assumed to engage in high-risk behaviour because they are often deployed away from their homes and families for long periods of time and because they are young. Their status in the community, living circumstances and peer group influences all contribute to the likelihood that they will become frequent clients of sex workers. However, interaction between the military and community is strictly controlled in some countries, and military personnel may have limited opportunity to engage in high-risk behaviour such as sex with sex workers and may do it rarely. Thus, the assumption that they are a population group engaging in high-risk behaviour may turn out not to be true or to be only partly true. This does not necessarily mean that military personnel should not be included as a surveillance subpopulation. It merely illustrates that levels and frequency of risk behaviour must be taken into account in setting priorities among surveillance subpopulations.

Determining whether a subpopulation is a population group with high-risk behaviour requires defining the subpopulation, such as (a) sex workers working in brothels and massage

parlors, (b) men who have sex with men who can be accessed at mapped cruising sites in urban areas, (c) women who trade or sell goods in border areas, (d) in-school youth and e) male miners. Deciding whether to give priority to a subpopulation for surveillance depends on the frequency of their risk behaviour relative to other subpopulations. Some subpopulations such as sex workers and injecting drug users have regular high-risk behaviour. Other groups, such as occasional clients of sex workers, may have less frequent risk behaviour. However, these groups may be important because they provide behavioural links to low-risk subpopulations. The next sections on pre-surveillance assessment discuss methods of determining risk and selecting groups.

## Size of the subpopulation

Although a subpopulation is known to be engaging in high-risk behaviour, the size of the subpopulation and its potential role in transmitting HIV should be carefully considered before the subpopulation is selected for surveillance. The size of a subpopulation can be explored by reviewing existing literature, the pre-surveillance assessment (discussed in detail in a later section) and by estimating the size of subpopulations (5). This does not mean that a particular subpopulation should be ignored if it turns out to be small. But it does mean that it may not be an appropriate subpopulation to include in a national surveillance system. Ad hoc surveys in the context of specific interventions might be more appropriate in this subpopulation.

## Additional considerations for choosing the appropriate groups

Although epidemiological considerations should be the foundation for selecting surveillance subpopulations, other considerations often influence the decision-making process. Governments may be reluctant to use resources on marginalized subpopulations such as injecting drug users and instead opt to focus on less politically controversial groups such as youth. Donor agencies may want the surveillance system to reflect their spending priorities. Implementing agencies may hope to use surveillance data to evaluate their own interventions.

Despite the frequently conflicting priorities of surveillance partners, the subpopulations selected should reflect those that are driving the epidemic in a given country; otherwise the overall purpose of surveillance is compromised. If the strategies of the national, donor and organizational programmes are seriously mismatched with the priorities of the most important subpopulations in the surveillance system, then this should be a signal that perhaps one or more of these bodies is missing the subpopulations most important in epidemic spread.

## Maintaining consistency across survey rounds

As discussed in previous sections, national surveillance systems have evolved over time, with behavioural and STI components sometimes being added to existing systems that measure HIV prevalence. Sometimes the subpopulations included in the various components of surveillance do not match. For example, serosurveillance might be conducted among sex workers who are treated at STI clinics, whereas behavioural surveillance is conducted among women who work in entertainment establishments. Whether the behavioural and biological components of surveillance are implemented in one integrated survey or in separate surveys, increasing the consistency in how the subpopulations are defined and sampled, the geographical areas covered and the timing of the surveys improves the chances that the trend data will be useful for understanding the dynamics of the epidemic. For this reason, the surveillance system must be periodically adjusted or even substantial redirected. Later this publication discusses the need for clearly defining the surveillance subpopulations for operational purposes to help maintain this consistency.

The decision to modify a surveillance system almost always interferes with the ability to measure trends over time. Decisions on selecting subpopulations have to be carefully balanced against the need for comparable trend data. However, the need for a trend line should not automatically take priority over the need to adjust the surveillance system so that it collects more relevant data.

### **Access to subpopulations**

Although who the key surveillance subpopulations need to be may be clear, the accessibility of these groups needs to be examined closely. Many subpopulations, such as injecting drug users, men who have sex with men, sex workers and cross-border migrants are hidden and difficult to include in surveillance, because no sampling frame exists for them or because the behaviour in which they engage is either illegal or so stigmatized that they prefer not to be identified or participate in providing data for surveillance. This, however, should not preclude including them in surveillance. Innovative sampling methods have been developed to reach these subpopulations, and the appropriate tools should be employed for hard-to-reach subpopulations (14,15). Maintaining a consistent, comparable study subpopulation is difficult when groups are hidden and in flux because of the influence of social and legal factors, but this can be overcome through careful planning during each surveillance cycle.

### **Donors and policy-makers**

The process of choosing subpopulations for surveillance is sometimes unduly influenced by donors wanting to fulfil reporting requirements or politicians not wanting to appear to be too supportive of groups with undesirable behaviour. This is somewhat of a vicious circle, because one of the main uses of surveillance data is to help donors and policy-makers get beyond preconceived notions about how to focus intervention efforts. This cannot be done in the absence of appropriate data on key subpopulations. Ideally, all concerned agencies and organizations should reach a consensus so that surveillance data can address everyone's needs to the degree possible without sacrificing the main objectives of the surveillance system. Consensus in advance also helps circumvent controversy when the data are released.

### **Ongoing or planned interventions**

Interventions should ideally be planned or in progress among the subpopulations included in surveillance, and data should be fed back into both the planning and implementation processes. However, it should remain clear that surveillance is not conducted for evaluating specific interventions but rather for guiding and monitoring the national response. When interventions overlap with surveillance subpopulations and geographical areas, then surveillance can provide valuable data to assess and at times evaluate the effects of intervention programmes, but national-level surveillance should not be designed around gathering data for any one specific intervention.

### **Minimizing harm to vulnerable subpopulations**

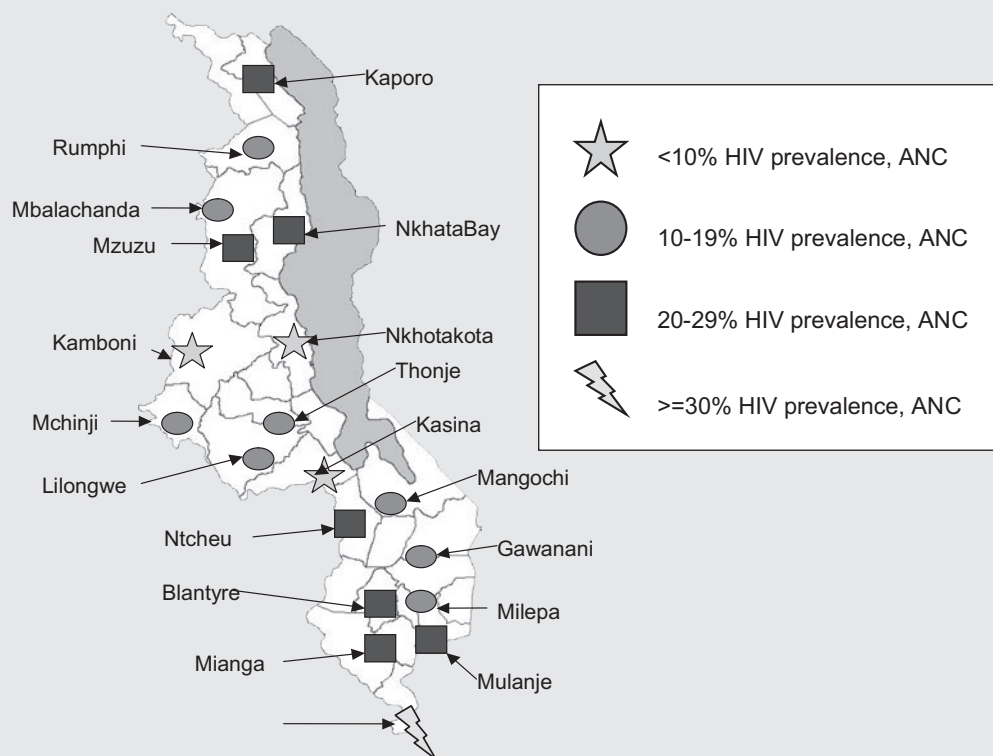
Surveillance often draws negative attention to subpopulations because of their sexual and drug-taking activities. Surveillance implementers should always consider what the adverse consequences might be to the subpopulations that are spotlighted in this manner. Is the data collected worth the increased danger or marginalization of a subpopulation? Sensitizing local authorities and communities can be helpful in alleviating the potential risks to a subpopulation, but implementers must make the welfare of the subpopulation a higher priority than their desire for information.

Very importantly, the subpopulations surveyed should not be expected to cooperate in surveillance efforts without benefiting from the information gathered, normally in the form of improved programming or provision of services. Creating false expectations or saturating groups with research when nothing is done to assist them undermines not only the research itself but also the trust the participants grant to the surveillance teams.

## Determining the geographical coverage area

The geographical coverage of surveillance should be determined by the pattern of spread of HIV (the locations where HIV is already spreading or is most likely to spread next). HIV epidemics do not begin at the same time, progress at the same rate or play out in the same manner in different places. If no data on HIV prevalence are available, reporting the levels of STIs or health facilities reporting a certain proportion of client visits due to STIs could be used as reference. In most countries with generalized epidemics, urban areas are affected before rural areas, and HIV prevalence is higher in urban areas than in rural areas. Most surveillance systems have therefore started in urban areas. However, over time, as HIV spreads to rural areas, rural sites also need to be included in the surveillance system. A secondary criterion for delineating geographical coverage is the administrative level (such as region, province or district) at which data will be most suited for action in terms of guiding and monitoring the response. If resources for health and human services are allocated and managed at the local level, then having data that are meaningful at that level may be more important than having them at a higher level. If high-quality data are available at a local level, they can usually be aggregated for use at a higher level (such as for national-level indicators). However, data collected at a national level cannot always be broken down into pieces that are useful at the local level.

**Fig. 3. HIV prevalence by district in Malawi among women attending antenatal care**



Source: Malawi National AIDS Commission, 2003.

Take the example of HIV prevalence data among antenatal care women in different regions of Malawi (Fig. 3). Would one national figure for a country situation such as this provide enough information for decision-making? If the purpose of surveillance was to report national indicators at the global level, then a single national geographical coverage area might be adequate. However, if the purpose is to understand local epidemic dynamics over time and use these data to make appropriate programmatic and policy decisions within a country, then carefully chosen subnational areas will yield more useful information while still referring to the national level.

## Choosing subnational coverage areas

At times, when financial and human resources allow, all geographical areas may be covered by a surveillance system. However, this is rarely feasible, so a clear system of geographical priority-setting is needed. Sometimes surveillance areas are grouped by region, with some geographical areas serving as proxies for others (when there is enough information about the areas to justify doing so). In low-level and concentrated epidemics, it is particularly important to understand which geographical areas have a high concentration of subpopulations with high-risk behaviour that may fuel HIV transmission now or in the future and therefore need to be targeted early for intensive intervention. This is another instance in which understanding subpopulation size is key. Migration patterns between high- and low-prevalence regions must also be considered when deciding on high-priority geographical areas.

A common misperception is that all high-risk subpopulations need to be represented in all surveillance areas. This is not the case. Data collection should be tailored to the specific data needs of specific geographical areas. So, for example, the presence of border traders clustered in a province near the border of a country with higher HIV prevalence does not mean that migrants need to be sampled in every region of the country. Likewise, among men who have sex with men, deciding to include them as a surveillance subpopulation does not mean they need to be included in every region where surveillance is done. If it is known that men who have sex with men with a higher prevalence of high-risk behaviour concentrate in selected urban centres, then surveillance efforts should be focused there.

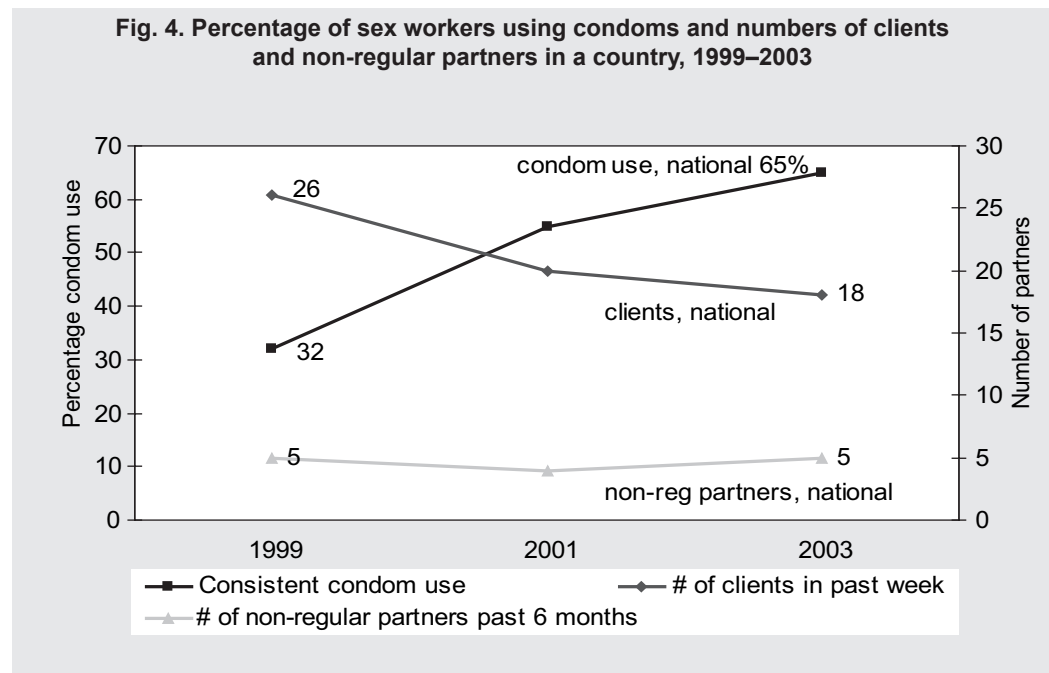
Box 3 indicates some of the issues to consider when determining where to perform surveillance.

### Box 3. Questions to answer in determining geographical coverage

- What is already known about the epidemic in different regions of the country?
- What are the regional differences in HIV transmission?
- Where are the subpopulations with the highest levels of high-risk behaviour concentrated?
- What are the estimated sizes of the subpopulations with high-risk behaviour in each geographical area?
- Are there cross-border or internal transport routes that could fuel transmission?
- How accessible are the various geographical areas?
- Can some areas serve as proxies for others, or does making informed decisions require knowing everything about every area?
- Is one national number enough to make appropriate programmatic and policy decisions?
- How much money and staff are available?
- What level of coverage is ideal?
- What level of coverage is feasible?
- Where are interventions concentrated?

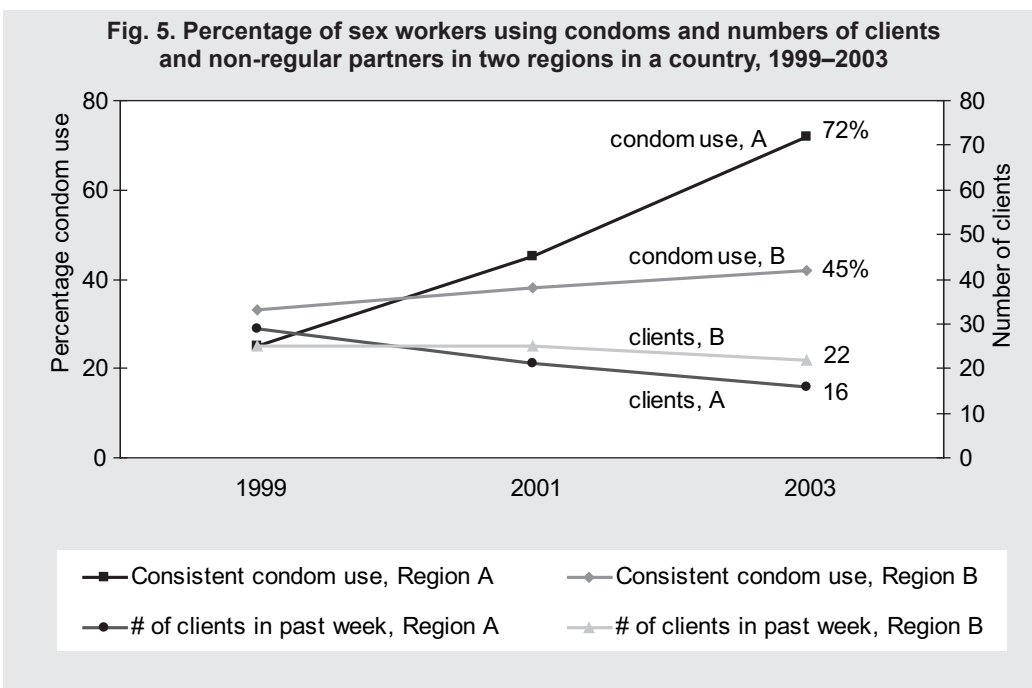
## Exercise in determining priorities in geographical coverage

Fig. 4 provides behavioural data from a national sample of sex workers in a country. Data were collected in 7 of 15 provinces in areas with high concentrations of sex workers, although the provinces not covered by surveillance have smaller pockets of sex workers. Based on these national data, how successful is the national response?



The national response in the country has in part focused on distributing condoms, increasing condom use in commercial sex partnerships and reducing the number of partners through client interventions and livelihood alternatives for sex workers. Although the number of non-regular partners sex workers reported remained stable over time, they reported one third fewer clients over a four-year period, indicating that their total number of partners probably decreased, in contrast to shifting from clients to non-regular partners. This could be due to an increased number of sex workers in the country and therefore fewer partners per woman, but data on men (not shown) support the assumption that fewer men have commercial sex partners and those that do visit less frequently than in previous years. An additional positive trend is that consistent condom use among sex workers and their clients rose from 32% in 1999 to 65% in 2003.

These data support the conviction of the national AIDS control programme that national response to the HIV epidemic in the country has been strong and appropriate. Fig. 5 looks at the same behavioural indicators broken out for the two most populous regions in the country. How successful is the regional response to the epidemic?



In 1999, sex workers in Region A had somewhat lower consistent condom use and more clients per week than the national average. The data show widespread behavioural change over the course of four years in Region A, with consistent condom use tripling and the number of clients of sex workers substantially reduced. This area of the country could indeed be considered a success story in accordance with the overall national response.

In contrast, Region B hovered above the national average for condom use among sex workers in 1999 but did not make strong inroads in increasing condom use in subsequent years. By 2003, condom use in the region had risen only slightly and the number of clients among sex workers was only somewhat lower than previously. Neither of the indicators in Region B displays the reductions in risk behaviour that were seen in the nationally aggregated data. Hence, national data would mask important behavioural differences across regions and the need to tailor policy and intervention activities to address these subnational disparities.

## STEP 4: CONDUCT FIELD ASSESSMENT

### **Gather information for making decisions on subpopulations and geographical areas and for implementing surveys**

Once a coordinating body has agreed on the purpose of the surveillance system, identified the data gaps and data requirements and agreed on criteria for selecting the subpopulations and geographical areas, the final locations and subpopulations can be selected. This section of the module provides guidance on how to do this systematically (although the process very often happens in a more ad hoc way in practice).

### **Identifying hotspots and subpopulations at risk taking into account what is currently known**

The process should begin by assessing what is currently known. Population-based household surveys on HIV-related risk behaviour (if they have been conducted) can provide valuable clues about which subpopulations or geographical regions merit further investigation by the surveillance system. If such data do not exist, countries should consider collecting them because they are needed to get the full picture of the potential for epidemic spread.

Other data sources that can feed into decisions about subpopulations and geographical locations include the existing surveillance system, reported HIV infections and AIDS case reports, rapid assessments, ad hoc surveys, evaluation studies, press reports and any other existing information on groups of people thought to be engaged in especially high-risk behaviour. These might include sex workers, clients of sex workers, men who have sex with men, injecting drug users and other men and women who have multiple sexual partners. These vary by social and cultural setting. They may sometimes, but not always, include mobile or migrant subpopulations or young people.

### **Conduct field assessment to confirm assumptions about hotspots and at-risk subpopulations**

Field assessment is very important for confirming that a) the selected subpopulations are actually engaging in high-risk behaviour and b) they exist in sufficient numbers to merit inclusion in the surveillance system. The field assessment should also investigate the feasibility of collecting data among these subpopulations by exploring a) how and where members of the subpopulation can be accessed and sampled systematically and b) the general willingness of potential respondents to participate in surveillance surveys. Such a process should feed into clear operational definitions of the subpopulations and the establishment of eligibility criteria for selecting survey respondents. For example, it is not enough to say that the surveillance system will include “men who have sex with men” or “female sex workers”. Such definitions can lead to ambiguous surveillance findings if they are not operationalized consistently in consecutive rounds of surveillance. To illustrate this, if a survey of men who have sex with men selects respondents from a sampling frame of cruising spots where men who have sex with men go to meet or solicit male sexual partners, it may find a higher proportion of men buying sex from men or having multiple male partners than would a survey sampling from among all men who have sex with men sampled by another method, such as respondent-driven sampling. This is not an inherent problem, unless men who have sex with men are defined differently in consecutive surveillance rounds or if there is no clear explanation of whom the

sampling universe is meant to represent. Such a situation can lead to considerable error in interpreting surveillance findings.

Assessing STI care-seeking behaviour and the proportion of visits at health centres for STIs may be useful as well.

## How should field assessment be conducted?

The field assessment gathers information to guide preparation of the main surveillance survey (whether it be a behavioural survey only, a biological survey only or an integrated biobehavioural survey). It may include some or all of the following:

- confirming that selected subpopulations are engaging in high-risk behaviour;
- determining the approximate size of selected subpopulations in selected areas of geographical coverage, which may involve preliminary mapping;
- gathering information that will help to define selected subpopulations, develop operational definitions and establish inclusion criteria;
- determining the feasibility of conducting surveillance in selected subpopulations, including accessibility, willingness to participate, potential harm to the subpopulation and possible sampling approaches; and
- gathering information to help guide the fieldwork, such as who the gatekeepers are, what languages are spoken, the patterns of movement and the locations and times of availability.

Ideally, time and resources permitting, this type of assessment should be conducted before the final surveillance subpopulations and geographical locations are selected and before determining details of the sampling design and field methods. Although some preliminary mapping may take place during the field assessment to get a rough idea of where to access members of the subpopulation and how many there are, detailed sampling frames should not be developed until the time of the survey, after final decisions are made about exactly who is to be considered as the sampling universe (the population to which results may be generalized). The sampling universe is defined by the combination of 1) the operational definition to be used for the subpopulation, 2) the inclusion criteria and 3) the area of geographical coverage.

The following section provides suggested ways to pursue each of these objectives. Annex 1 provides more detailed guidelines and some sample instruments for data collection.

### ***Confirming that subpopulations are engaging in high-risk behaviour***

The purpose of this step is to provide evidence that the selected subpopulation is actually at risk of HIV infection. One way to approach this is to interview a selected sample of gatekeepers and key informants who are familiar with this subpopulation. Another approach is to interview members of the proposed subpopulation themselves. The interviews should be open-ended but cover a range of predetermined topics. They should be designed to elicit information about risk behaviour that could lead to exposure to HIV, such as the likelihood of having unprotected sex with multiple partners, engaging in commercial sex or sharing needles and syringes. There is no specified number of people to be interviewed at this stage. The goal is to continue interviewing people until no new information emerges.

A rule of thumb for each area of geographical coverage might be to interview at least five key informants (including gatekeepers) and five subpopulation members, with the possibility of interviewing more if the information gathered is still insufficient.

***Determining the approximate size of the selected subpopulations in selected areas of geographical coverage, which may involve preliminary mapping***

An exact count of the selected subpopulation members is not required at this stage. What is needed is a rough estimate of how many members of the subpopulation can be found in this area of geographical coverage. There are a few different approaches to obtaining these estimates.

1. One is to ask key informants to make their best guess and then take the average of the various responses. However, if the guesses vary widely, this then poses a problem. Nevertheless, it should be possible to at least get an idea within an order of magnitude (for example, is the estimate closer to 10, 100, 1000 or 10 000 people?). This type of information should provide some guidance about whether the subpopulation merits being included in the surveillance system. “Small” does not necessarily mean “unimportant”, but the question should at least be asked about whether surveillance is the most effective means of addressing this subpopulation.
2. Another approach to estimating size is to preliminarily map locations or sites where subpopulation members gather and obtain a count of how many are present at the time of the visit. However, this method has several limitations. One is that the number of members present at any one time may not be at all representative of the number of different members who frequent the site over a period of days, weeks or months.

Also, depending on the type of subpopulation, members may frequent several different sites (such as sex workers, clients of sex workers, injecting drug users and men who have sex with men), so those appearing at one site on one day may be the same as those appearing at another site later the same day or on another day. Simply summing up the number of people found at all the sites will therefore not necessarily provide a good estimate of the total subpopulation size or even a rough estimate.

One way to deal with this is to interview key informants and subpopulation members at the sites to get an idea of how many subpopulation members visit the sites on different days, and whether the flow of the subpopulation varies at different times (such as different days of the week or different times of the year). You can also get a sense about how much people move around between the sites and the likelihood of double-counting subpopulation members at more than one site.

Another limitation is that identifying the members of the subpopulation of interest at a given site is sometimes difficult. For example, if the operational definition of the subpopulation is women who work at certain types of venues (such as truck stops, beer or dancing halls, karaoke lounges or massage parlors) and the eligibility criteria is those who have sold sex within the past month, they cannot be identified without talking to them (or to a key informant). Likewise, if the subpopulation of interest is men who sell sex to men, they cannot be identified without interviewing them. To take a different kind of example, if the subpopulation is young male vendors who are single and out of school, assessing how many young male vendors are single or out of school in a given location (such as a marketplace) without talking to them would be difficult.

Finally, for the subpopulations that do not gather at identifiable locations, making even a rough estimate may be impossible, which is why at this stage, dealing only with orders of magnitude may be necessary. Nevertheless, gauging the size of a subpopulation before selecting it for surveillance is important, because attempting surveillance in very small (or nonexistent) subpopulations can be very frustrating and not very useful (5).

### ***Gathering information that will help to define selected subpopulations, develop operational definitions and establish inclusion criteria***

One of the biggest sources of error in surveillance is the failure to track subpopulations consistently over time. This sometimes happens because the subpopulation has not been defined in sufficient detail. Take sex workers as an example. Sex workers can be defined and sampled in many different ways. Some countries use all women with STIs visiting a clinic as a proxy group for female sex workers. Or they may screen women with STIs to find out which ones sell sex and use that group as the surveillance subpopulation. Others sample women directly from brothels. Others recruit women who work in hotels (whether or not they sell sex), and still others recruit women who have been arrested for prostitution. These are only a few examples. If the method for recruiting sex workers for surveillance is not consistent over time, then interpreting the trend data becomes difficult. That is why it is critical to have a clear operational definition of what is meant by a female sex worker and to have specific eligibility criteria determining who should and should not be included in surveillance surveys. The information gathered during the pre-surveillance field assessment can help inform surveillance planners about the nature of commercial sex (how, when and where sex workers operate). This information can then be used to decide how best to define the subpopulation for surveillance. The section on finalizing subpopulations and geographical coverage provides more detail about operational definitions.

### ***Determining the feasibility of conducting surveillance in selected subpopulations, including accessibility, willingness to participate, potential harm to the subpopulation and possible sampling approaches***

In preparation for the main surveillance survey, the field assessment needs to address the willingness of subpopulation members to consent to participate in surveillance (behavioural, biological or both) and what conditions are needed to enhance cooperation. This is always a challenge because participants often expect to be compensated monetarily for participating in surveys. One thing to assess is therefore what will motivate people to participate.

It is important to ensure that surveillance activities benefit the subpopulation being surveyed and that members of the subpopulation can perceive the benefits. This process begins with community mobilization (preparing the community) at the time of the assessment. Willingness to participate may differ depending on whether the surveys are behavioural only or whether they include collection of biological specimens such as urine, blood or genital swabs (which require a speculum examination for women and a physical examination for men). Some procedures can be highly invasive, so assessing acceptability is important before investing substantial time and resources.

In designing the sampling approach for the main survey, the first thing to be assessed is whether a high proportion of subpopulation members are accessible through identifiable locations that can be listed and/or mapped. If the answer is no, then this

has very important sampling implications because it means that probability sampling may not be possible (unless respondent-driven sampling is done).

In the past, the most common methods of sampling hard-to-reach subpopulations were non-probability sampling techniques. The problem with these methods is that they limit the ability to generalize information and track trends over time. More recently, there have been some promising developments in probability sampling that offer alternative approaches to the more traditional venue-based sampling. One such method is respondent-driven sampling (2).

This method allows for selection of a probability sample, even when subpopulation members cannot be listed or accessed through identifiable locations. This method may be very useful in situations in which the proportion of subpopulation members accessible at identifiable locations is not known. In such situations there is a risk of missing large segments of the subpopulation that never appear at the sites. Using respondent-driven sampling can help assess the composition of the subpopulation of interest, leading to better knowledge of who is being missed with venue-based sampling.

***Gathering information to help guide the fieldwork, such as who the gatekeepers are, what languages are spoken, the patterns of movement and the locations and times of availability***

Finally, for the subpopulation selected for surveillance, specific information is needed about field conditions before finalizing the protocol for data collection. This information can be gathered at the time of the field assessment.

What types of information are needed?

1. An important first step in preparing the fieldwork is to know who the gatekeepers and key players are and to approach them as partners in the surveillance effort. Consider whose permission will be needed to conduct surveillance (aside from that of the respondents). Who can help facilitate access to the subpopulation and ensure the smooth progress of the survey? Whose toes might be stepped on if outside researchers come into a community to conduct a survey?
2. At this stage, determining how, when and where interviews and specimen collection can be done with this subpopulation is also important. Information will be needed on all of the following.
  - In what language will survey interviews need to be conducted?
  - What is the desired profile of the interviewers to ensure the most valid study results in the main surveillance survey? This aspect is often downplayed, but it should not be. After all, none of the surveillance efforts will amount to anything if the people who come in contact with the survey respondents cannot obtain valid data. Aside from ensuring that the survey staff are competent to do their jobs, some other things to think about are whether the interviewers should be male or female. Older or younger? Government workers or not? Health care professionals or not? University students or not? People from within the local community or not? Even the dress code and demeanor of the interviewers is important to consider because respondents should be made to feel as comfortable as possible. Otherwise they will not be able to speak freely and the results of the surveys will be compromised.

- What will be the possible locations where surveillance data collection will be able to take place where privacy will be ensured?
- What will be the best times of day to find people who can be recruited to participate in the survey and to ensure that they will have time to go through a consent process, be interviewed or provide specimens?

Annex 1 provides examples of data collection instruments for pre-surveillance field assessment.

In locations where PLACE (priorities for local AIDS control efforts) surveys have been conducted (15,16), these can be quite helpful in characterizing risk subpopulations in specific geographical areas.

## STEP 5: FINALIZE THE SELECTION OF SUBPOPULATIONS AND GEOGRAPHICAL COVERAGE

After careful planning and fieldwork, all the information gathered needs to be synthesized for final selection of subpopulations and geographical coverage. This is one of the key roles of the surveillance coordinating committee, and the members must agree that they are not only committed to the final selection of subpopulations but will also advocate for releasing and using the data widely. In instances where groups such as injecting drug users and men who have sex with men are stigmatized and policy-makers would prefer not to deal with them, the coordinating body must carefully weigh whether surveillance is the right method for reaching the group. If surveillance is truly owned by the national AIDS committee, then they must be prepared to follow through on disseminating and maximizing the use of the data, despite the wishes of some decision-makers, as well as protecting the best interests of the subpopulation. This needs to be strongly considered in subpopulation selection, and at times the coordinating committee might agree that a subpopulation can be better served by collecting data through more specialized surveys.

### Review the assessment information against the criteria for selecting subpopulations

After the field assessment is complete, the data collected through the literature reviews and field assessment should be synthesized and presented in a manner that will allow the coordinating committee to determine whether a subpopulation or geographical area fulfils the selection criteria. This is best done in a working group meeting at which the field teams present their findings and a member of the coordinating committee facilitates a discussion on what subpopulations and regions fulfil the final selection criteria (Box 4).

#### Box 4. Criteria for final selection of subpopulations and geographical coverage

- Will the subpopulation contribute to fulfilling the purpose of surveillance: for example, tracking behaviour, STIs or HIV in the general population and in the population groups with highest levels of risk behaviour?
- Can the subpopulation be defined and reached?
- Is the subpopulation large enough to make it a priority?
- Is this a current surveillance subpopulation, and can trend data be gathered?
- Are there interventions among this subpopulation, and if not, are they an important subpopulation being missed?
- Will surveillance benefit the subpopulation? Or will it cause more harm than good?
- What components of surveillance can or should be carried out among each subpopulation (HIV, STI and/or behavioural)?
- Do the geographical regions cover the epidemic hotspots, and how do they compare with the regions not selected?
- Does the coordinating committee agree on the subpopulations, and is it committed to releasing and using the data?
- Are there adequate financial and human resources for surveillance in all the subpopulations and geographical areas? If not, which are the priorities and why?

A system for vetting surveillance subpopulations is absolutely mandatory. Box 4 shows examples of questions that need to be answered in selecting subpopulations, but they are not all-inclusive. Surveillance coordinating committees need to decide what system they

will use to narrow down and then make final decisions on subpopulations and geographical coverage before engaging in the process. Although having information about many, many subpopulations would be nice, this is not necessary for monitoring the overall course of the epidemic – as long as the subpopulations are chosen wisely. Remember that, although surveillance is important, the more time and funding are allocated to surveillance, the less is left over for the all-important interventions.

Sometimes donors offer to fund surveillance in particular provinces or subpopulations. This should not dissuade the coordinating committee from going through the full process of selecting subpopulations and regions. The coordinating committee should make decisions on subpopulations and provinces based on epidemiological criteria first. Then donors should be encouraged to buy into the surveillance system, as the system will often cover their priority groups or areas.

If this is not the case and there is considerable intervention activity in regions not included in surveillance, then the reasons that overlapping coverage has not occurred need to be considered. Is the surveillance system missing something or are the implementers missing something? In the end, leveraging national and international funding for surveillance is far easier if the system is well planned than if it is held captive to answering to the selective needs of particular organizations.

## Develop clear operational definitions

After the information has been reviewed, the final subpopulations can be selected. The subpopulations commonly associated with transmission of HIV will usually be included (for example, sex workers and drug users). However, even these groups need to be clearly defined, and other subpopulations should also be considered such as “clients of sex workers” and “migrants”, both very difficult to define and access for surveillance purposes.

Operation definitions clearly explain who the subpopulation is. They often describe a population group through risk-taking behaviour, occupation, movement pattern or utilization of health facilities (such as people attending STI or antenatal care clinics). These definitions must be concise to understand the exact population universe, to determine the sampling methods, and – very importantly – to measure trends in the same population over time.

## Examples of operational definitions: good or poor?

### Men who have sex with men

Poor definition: men who have anal intercourse with other men

“Men who have sex with men” is one of the most complicated and vague subpopulations to define. This definition would include all men who had had anal intercourse with other men at any time in their lives. In this case, returning to the purpose of surveillance and the subpopulation selection criteria is important. Why are men who have sex with men of interest for surveillance? Unprotected anal intercourse is an efficient HIV transmission route, and men who have multiple sex partners – male as well as female – are highly vulnerable and may act as a bridge for transmission of HIV to other subpopulations. Some subpopulations of men who have sex with men have higher levels of risk behaviour than others. If these subpopulations are the groups of interest for surveillance, then this needs to be made clear in the operational definition.

Better definition: men in urban areas older than 15 years who have solicited commercial and non-commercial male sex partners at cruising sites in the past year.

This restricts the definition to men who may have multiple male sex partners. The geographical scope can also be limited to men in urban areas. This definition is not without its problems, however. How can one determine whether they are buying or selling sex? Where can they be reached? How should they be sampled? Operational definitions for men who have sex with men must take all of this into consideration, and sometimes the definition might have to be adjusted to what type of sampling is feasible. Clearly, surveillance among men who have sex with men requires a very detailed assessment before being launched.

## Male seasonal migrant workers

Poor definition: men engaged in labour migration in neighbouring countries who periodically return to their home communities

The pre-surveillance assessment should have provided considerably more information about who these men are, from where they are migrating (their source communities), to where are they migrating (their destination communities), in what forms of labour are they engaged, what their risk activities are and how frequently they return to their source communities, among other things. If this information is not known, the subpopulation cannot be adequately defined let alone reached for the purpose of surveillance.

Better definition: men aged 15–49 years who work as unregistered labourers in a given country for at least three months a year and return to their home communities at least once a year.

This definition includes a wide range of cross-border migrants and sets parameters for what type of migration is considered more risky for the men and their home communities. If not enough is known about their exact occupation in another country, then this type of information can be asked about during the field assessment. The assessment should have identified where these men live so the geographical coverage area can be correctly determined. It should also have indicated when the men are likely to return home so that data collection (if it is conducted in source communities) can be timed accordingly.

Subpopulation selection does not have to be fully finalized before developing operational definitions. The process of creating definitions often helps in selecting the subpopulations. For example, if you are defining potential sex worker client subpopulations and the field assessment or general population information identifies multiple client groups, you cannot (and need not) select all possible client groups (such as military personnel, police officers, truck drivers, government workers, schoolteachers, fisheries workers, construction workers, tea plantation workers and stone cutters). A subset of these should suffice. The assessment process might show that some groups are more frequent clients than others or that they are very similar. In determining the operational definition, some clients may be easier to categorize and sample, and they might serve as a proxy for a more imprecise client group.

If no one subpopulation jumps out as having a high proportion of members who buy sex, then clients of sex workers sampled directly from sites where sex is sold might be considered a surveillance subpopulation. Sometimes that might be the only politically acceptable approach, even though the subpopulation to whom the data can be generalized is less clear.

## Standardized versus country-specific definitions of subpopulations

Just as national instead of subregional indicators are often measured for global reporting requirements, subpopulations are sometimes selected based on excessively standardized definitions in reporting guidelines. The pre-surveillance process shows that each country is unique. Certain types of behaviour drive HIV transmission, but the subpopulations engaged in this behaviour do not fit into one universal mould.

Surveillance needs to be useful to the country, and defining subpopulations based on what a neighbouring country is doing only for the purpose of comparison does not benefit the country. Very clear definitions of subpopulations go far in alleviating the sometimes fractious relationship of subnational, national and international priorities. For example, young food vendors in a given country may have a higher level of risk behaviour than other out-of-school youth. If that is what they are – young food vendors – then call them that. Do not call them (and report them as) general population youth solely to fill in a box. Further, do not drop them from the surveillance system in favour of general population youth if the epidemic has not progressed to the point where including all youth is necessary.

Nevertheless, indicators compared across countries and continents provide a powerful tool for charting the changing stages of the epidemic in different areas of the world and determining what intervention strategies may (or may not) be working. Clearly defining surveillance subpopulations when reporting indicators allows international organizations to determine what is and is not comparable.

## Conclusions

This publication has attempted to lay out a process by which countries can plan for surveillance systems that will allow them to 1) understand their evolving HIV epidemics, 2) respond with intelligence in ways that will counter HIV spread, 3) know where their programmes are succeeding and failing and 4) stockpile ammunition needed to advocate for policies that support rather than undermine efforts to reduce the spread of HIV and 5) mobilize sufficient resources to respond.

While international guidelines for HIV surveillance have contributed to the presence of surveillance systems that are better tailored to specific epidemic conditions, many countries still do not have the data they need to understand how their epidemics are evolving or where to focus their efforts so as to stop the spread of HIV.

Data gaps exist because of poor planning, insufficient attention to quality control and resources wasted on duplicate data collection efforts while gaping data holes are allowed to remain unfilled. Partners with resources for surveillance are increasingly giving priority to their own data needs: collecting evidence that relates directly to their own programmes without regard for whether enough is being done in the country as a whole to reduce the epidemic.

These types of problems would not need to exist if surveillance partners synchronize their efforts through a coordinating body led by the national AIDS control programme, which would help identify data gaps and set priorities among data needs. In addition, putting time and resources into careful planning for surveillance is vitally important, so that appropriate choices can be made about when, where and among whom to conduct surveillance, as well as which data to collect and which methods to use.

Awareness of the importance of pre-surveillance activities has grown and has become embedded in the surveillance methods in many countries. The guidance laid out here is the result of experience gained from efforts in many countries to plan effectively for surveillance and ultimately for the best possible response to the HIV epidemic.

# ANNEX 1. GUIDANCE ON CONDUCTING THE FIELD ASSESSMENT

The field assessment involves mostly qualitative data collection techniques, including in-depth interviews with key informants and observations. As described in the module, the field assessment is designed to gather information on any or all of the following:

- confirming that selected subpopulations are engaging in high-risk behaviour;
- determining the approximate size of selected subpopulations in selected areas of geographical coverage, which may involve preliminary mapping;
- gathering information that will help to define selected subpopulations, develop operational definitions and establish inclusion criteria;
- determining the feasibility of conducting surveillance in selected subpopulations, including accessibility, willingness to participate, potential harm to the subpopulation and possible sampling approaches; and
- gathering information to help guide the fieldwork, such as who the gatekeepers are, what languages are spoken, the patterns of movement and the locations and times of availability.

## Example

Imagine you were investigating how to define female sex workers and determining whether more than one surveillance subpopulation was needed. There would be little point in interviewing people randomly selected from the subpopulation to answer your question. Instead you would need to determine who could best provide you with the information you needed. Informants might include sex workers, nongovernmental organizations who work with sex workers, brothel and bar owners and pimps, among others. Once the type of informant is determined, the people to be interviewed should be selected based on their competence as an informant. A good informant is someone who is knowledgeable about the topic, can be talked to easily, understands the information you need and is willing to give it to you.

Unlike quantitative surveys, the sample size for qualitative research is not calculated prior to data collection. A common way of determining the sample size in qualitative research is known as theoretical or saturation sampling. This involves continuing to interview informants until no new information is learned. We could, for example, ask informants to list all the different types of places they know where women sell sex. When the lists begin to be repetitive and informants are not providing new information, an adequate sample size has been reached. Among those involved in sex work, the types of sex workers can be considered common cultural knowledge, and a complete list of these types can probably be compiled from a handful of good informants.

Once the various types of sex work have been identified, the question of whether they need to be separated into different surveillance groups can be considered. This requires understanding whether the type of sex work affects risk and transmission. This is best explored using open-ended semistructured questionnaires. Open-ended questions have no predetermined responses from which the respondents can choose. Instead respondents can respond spontaneously and in their own words. Using open-ended questions allows topics to be covered in more depth and can stimulate thoughtful responses and probing by interviewers. Probing is often necessary to avoid incomplete or irrelevant responses that cannot be interpreted. Interviewers are encouraged to deviate from the guide when necessary to follow up new leads

on the topic. These methods are in contrast to quantitative research, which tries to ensure that each informant is asked exactly the same questions in exactly the same way.

If, for example, an investigation uncovered two major kinds of sex, brothel-based and street-based, before classifying one or both as a surveillance subpopulation you would want to know such things as whether street-based sex workers work routinely or only occasionally, whether they work the same streets or were constantly shifting, whether they also worked in brothels sometimes and whether they had many clients or only a few. These and other issues could potentially affect the risk profile and feasibility of selection as a surveillance subpopulation.

## Sample forms for field assessment

Form A below provides an example of a structured open-ended interview guide for interviewing key informants when gathering information during a field assessment for female sex workers. Similar forms would be needed for other subpopulations, but they would have to be tailored to that subpopulation.

### Instructions to the field team

The following are potential key informants for establishment-based female sex workers (the list is not exhaustive and depends on the context):

- owners of bars, clubs and brothels;
- bartenders;
- vendors near the establishment;
- patrons in the establishment;
- pimps (especially for street-based sex workers);
- police (supplemental information on the number and location of sex workers);
- taxi drivers; and
- staff of government or nongovernmental organizations working with female sex workers.

## Form A. Collecting information to guide fieldwork

### In preparation for surveillance among female sex workers

#### *Introduction (to be read to the person being interviewed)*

The Ministry of Health of [country X], through [name of research agency] in close collaboration with the [National AIDS Committee] of [country X] is conducting [[behavioural surveillance] or [integrated surveys of behaviour, HIV and sexually transmitted infections]] in [country X] among female sex workers in [year of survey]. We need to investigate some important issues before launching this surveillance effort so that we can collect the most useful information. I would like to discuss these issues with you to help us design our survey. The information you and I discuss today will be kept strictly confidential, and your name will not be recorded or associated with it in any way. Do you agree to be interviewed?

(If the person agrees, then begin discussing the topics outlined below.)

Region or province where the field assessment is being conducted:

\_\_\_\_\_

[Codes specific to country]

City or town:

\_\_\_\_\_

[Code for area of geographical coverage]

#### Topics to be covered during the interview or conversation

##### 1) Sites where sex workers find clients

The purpose is to obtain an exhaustive list of the various types of locations where female sex workers are looking for clients (and vice versa). This will be done by having interviewers ask key informants about locations and probing for all possible responses. This can be followed up with observations at those venues on different days and at different times.

The information gathered will be used to decide what different types of sex workers there are in this area, how they might be divided into population groups and the best type of sampling approach to use for the main survey. The interviewer should probe to find out whether most sex workers use sites or venues to find clients or whether there are indirect channels, such as mobile telephones, the Internet, pimps or others. This will help determine what will be the best sampling approach.

##### 2) Peak days and hours for sex work, mobility and migration

The purpose is to find out the most common days of the week and times of the day when women selling sex are present at the sites named above. (On this form the question is a general one, but later, during sampling frame development, detailed information from each individual site is needed.) Interviewers should probe to find out whether women tend to work out of one site or whether they move around from site to site. If they move, how often do they move? Are they present in several different sites in one day? Do they work at different sites on different days? Do they move between districts or areas of geographical coverage? For example, do they work for several weeks or months in one district, province or hotspot and then move to a different one? Or do they remain in one district?

The information gathered here will be used to help determine the exact times when the teams will go to the field during the main survey. It will also be used to help decide whether sites should be sampled once or multiple times, by helping to understand whether different women are present at the sites on different days or whether the same women are present over and over again if the site is visited multiple times. In addition, determining whether women move between areas of geographical coverage will also determine whether the same women are likely to be sampled in different areas.

##### 3) Setting for the interview or specimen collection

The purpose is to gather information about the ideal conditions for the interview or specimen collection. During this part of the discussion, interviewers should find out whether female sex workers are willing to be interviewed for 30–40 minutes about their sexual behaviour (that is, is it feasible to do this), and if so, what would be the ideal time of day and the ideal location for the interview. They should also find out whether sex workers would be willing to give biological specimens (such as blood

or urine) or undergo physical examination (speculum exam) to look for sexually transmitted infections and, again, what would be a good location for doing this part of the survey. (The key informants may not be able to provide this information, so it is not necessary to discuss this with every key informant.)

Interviewers should also find out what languages the survey staff will need to speak, by determining the language most comfortable for the sex workers. If any sex workers do not speak the local language or languages, this should also be noted. Finally, interviewers should attempt to find out the type of interviewers with which the sex workers would be most comfortable speaking (male or female, older or younger, local or not local, government workers or not, health care workers or not, how they should be dressed, etc.).

The information gathered here will be used to help plan the main survey in terms of where and when to collect data, what type of interviewers to hire, what language skills will be necessary, etc.

#### 4) Types of sexual partners

The purpose is to find out what type of sexual partners female sex workers have and what they call them. This should be an open-ended question. Let them define the partner types. Do not do it for them. However, it may be necessary to probe to find out what types of clients they have (regular or one-time clients). What sexual partners do they have who are not clients? These may be boyfriends, casual acquaintances or other types of regular partners such as spouses, live-in partners or female partners. Interviewers should try to find appropriate terms to refer to these different types of partners so that the female sex workers easily understand the terms. If possible, interviewers should also probe for information about the types of intercourse engaged in (vaginal, anal or oral). This does not have to be discussed with every informant, but if the conversation is comfortable and flowing easily, then these types of questions can be addressed.

The information gathered here will be used to refine the questionnaire for the female sex workers during the main survey.

#### 5) Number of sex workers

The purpose of this part of the discussion is to determine approximately how many women sell sex in this area of geographical coverage. An exact number is not needed, but rather a range. For example, are there "more than 50 but less than 100" female sex workers in this area? If more than 100, are there at least 1000? Or are there more than 100 but far fewer than 1000? Does this number vary by season: for example, would there be fewer after the rainy season?

The information will be used to help surveillance planners know approximately how many sex workers will be available to be interviewed in each area of geographical coverage, which will help in planning the fieldwork.

**At the end of the discussion, please check to make sure you have covered all the topics.**

**Please be sure you have recorded the name of the region, the city or town and the area of geographical coverage on the interview form.**

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