Introduction to HIV, AIDS and Sexually Transmitted Infection Surveillance

Surveillance of Most-At-Risk Populations (MARPS)

Participant Manual

September 2012

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Introduction

How to Study This Module

What you should know before the course

This course builds upon the information provided in the training module titled "Surveillance of HIV Risk Behaviours." This course is meant primarily for those involved in the planning and implementation of HIV surveillance in most-at-risk populations (MARPs). As a participant, you should understand the basic epidemiology of HIV and public health surveillance.

Module structure

This module is part of a set of six modules that have been designed for use globally in HIV surveillance training workshops. The other modules are:

- Overview of the HIV/AIDS Epidemic with an Introduction to Public Health Surveillance
- HIV Clinical Staging and Case Reporting
- HIV Sero-Surveillance
- Sexually Transmitted Infection Surveillance
- Surveillance of HIV Risk Behaviours

Similar training modules have been developed for the WHO African (AFRO), Americas (AMRO), European (EURO), Eastern Mediterranean (EMRO), and South and Southeast Asian (SEARO) regions. These modules were developed to capture the global epidemic for use in trainings around the world.

This module is divided into units. The units are convenient blocks of material for a single study session. This module also can be used for self-study.

Because you already know quite a bit about HIV, we begin each unit with some warm-up questions. Some of the answers you may know. For other questions, your answers may be just a guess. Answer the questions as best you can.

You will keep the warm-up questions in this manual. No one will see your answers but you. We will study and discuss the unit, and then you will have time to go back and change your warm-up answers. At the end of the unit, the class will discuss the warm-up questions. You then can check your work.

Module structure, continued

As you study this module, you may come across italicised terms that are unfamiliar. In Appendix B, you will find a glossary that defines these terms, as well as acronyms and abbreviations that you may not recognise.

Module summary

This module provides an introduction to surveillance in populations at high risk for HIV transmission. The module is intended for use worldwide: Africa, Asia, Caribbean, Eastern Europe and Central Asia, Eastern Mediterranean, and Latin America.

Appendices

More information is provided:

Appendix A, References and Further Reading Material*
Appendix B, Glossary and Acronyms*
Appendix C, Useful Links*
Appendix D, Answers to Warm-Up Questions
Appendix E, Laboratory Tests Available for Measuring Biological Outcomes among High-Risk Groups

* Appendices A, B, and C are the same for all the modules.

Additions, Corrections, and Suggestions

Would you like to suggest changes to this module? Is there additional information you'd like to see? Please write or email us. We'll collect your suggestions and consider your comments in the next update to this module.

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Unit 1

Introduction to Surveillance of Most-At-Risk Populations

Overview

What this unit is about

Unit 1 introduces HIV surveillance in most-at-risk populations. This unit discusses the special ethical considerations of conducting behavioural and sero-surveillance in high-risk groups, as well the sampling approaches best suited for high-risk populations.

Warm-up questions

1. Which of the following groups are at high risk for HIV infection worldwide?

   a. sex workers
   b. injecting drug users
   c. men who have sex with men
   d. all of the above

2. True or false? In low-level epidemics, surveillance of most-at-risk populations can serve as an early indicator of the presence of HIV in a country.

   True False

3. List the two sampling methods that are commonly used in HIV surveillance of most-at-risk populations.

   a.
   b.

4. What are some potential consequences of not protecting participants' privacy and confidentiality?

Introduction

What you will learn

By the end of this unit, you should be able to:

- discuss the importance of surveillance in most-at-risk populations (MARPs) in different epidemic settings
- identify MARPs in your region
- discuss the advantages and disadvantages of different sampling approaches, especially in the context of surveillance among MARPs
- understand the special ethical issues of surveillance among MARPs.

Background

Public health *surveillance* for HIV is the systematic and regular collection of information on the occurrence, distribution, and trends in HIV infection. Surveillance data should be as accurate and complete as possible so that it may be analysed for effective prevention and control of the HIV epidemic.

Second-generation surveillance

Second-generation surveillance refers to activities beyond what are generally a part of routine surveillance, such as case reporting and sentinel *sero-surveys*. Second-generation surveillance uses additional sources of data to gain a better understanding of the epidemic. It includes *biological surveillance* of HIV and other *sexually transmitted infections* (STIs), as well as *systematic surveillance* of the behaviours that spread infection.

An important part of second-generation surveillance systems is determining HIV *prevalence* in groups that are at high risk of infection. These groups of people are most at risk for transmitting HIV or contracting HIV. The groups may be defined by the following:

- the presence or absence of HIV infection
- the presence of risky behaviours that create transmission events
- an occupation or *socio-economic status* that can be associated with *risk behaviours*.

Populations at high risk for HIV transmission

Sometimes referred to as *at-risk groups* or *high-risk groups*, members of *most-at-risk populations* (MARPs) are at increased risk of passing HIV on to others or of contracting HIV. They often are important in establishing, accelerating, or sustaining the HIV epidemic. Therefore, it is essential to understand the effect that HIV has had within these groups.

Throughout the world, *sex workers* (SWs), *injecting drug users* (IDUs) and *men who have sex with men* (MSM) are considered to be populations most at risk. Other MARPS include, but are not limited to, the following:

- mobile populations (such as migrants, refugees, and internally displaced persons)
- *street children*
- prisoners
- uniformed personnel.

MARPs are likely to be the first to get HIV infection in a new epidemic. They are infected at higher prevalence rates than the *general population*. In other words, a population at increased risk will become infected at a faster rate than the general population, which is defined as people who are not members of a sub-population at increased risk.

Populations at high risk for HIV transmission

For information on the issues unique to a specific at-risk group, refer to the unit related to the populations that interest you.

Table 1.1. Most-at-risk populations discussed in Units 2 through 9.

Group	Unit
Sex workers (SWs)	2
Injecting drug users (IDUs)	3
Men who have sex with men (MSM)	4
Mobile populations	5
Street children	6
Prisoners	7
Uniformed personnel	8
Out-of-school youth	9

A central role

Populations at increased risk play a central role in the spread of HIV infection. At the beginning of an HIV epidemic, the first infections appear in these groups because they have higher-risk behaviours including:

- having sex without using a condom (*unprotected sex*) with multiple partners and/or having many new partners
- injecting drugs with shared needles.

HIV then is transmitted quickly to other members of these groups through their *networks* of sexual and injecting drug partners. If, for example, an HIV-infected person shares a needle with a group of drug users, the entire group or network may be exposed to HIV through this needle.

Bridges

Populations at increased risk also serve as *bridges* from other groups and the general population because they can introduce HIV into these groups. A client of an HIV-infected SW, for example, may get HIV infection. He may then have unprotected sex with his wife, infecting her. In this scenario, he has acted as a bridge by which HIV infection has passed from the SW to his wife.

Epidemic states

Data from HIV surveillance in MARPs are used differently at different *epidemic states*. This use is illustrated in Table 1.2, on the next page.

Table 1.2. Uses of HIV surveillance data in most-at-risk populations for different states of the epidemic.

Epidemic state	Situation	Uses
Low-level	▪ HIV has not reached significant levels in high-risk groups ▪ HIV is largely confined to people within MARPs who exhibit higher-risk behaviours	▪ Early warning of a possible epidemic ▪ Begin interventions to prevent HIV infection in MARPs
Concentrated	▪ HIV has spread rapidly in one or more MARP ▪ Epidemic is not well established in the general population	▪ Monitor infection in MARPs ▪ Monitor effects of intervention programmes on HIV prevalence and behaviours
Generalised	▪ Epidemic has reached a level where transmission occurs in the general population; it is no longer dependent on MARPs to spread ▪ Without effective prevention, HIV transmission continues at high rates in populations at increased risk ▪ With effective prevention, prevalence will generally drop in MARPs before it drops in the general population—for example, following a successful prevention campaign for SWs, surveillance first should find a decrease in STIs in the SWs, then in male *sentinel populations*, and then in antenatal clinics	▪ Monitor for initial decreases in HIV prevalence in MARPs ▪ Monitor effects of intervention programmes on HIV prevalence and behaviours

Discussing the table

Looking at Table 1.2, on the previous page, answer the following questions:

a. How is HIV surveillance in high-risk groups used in low-level epidemics?

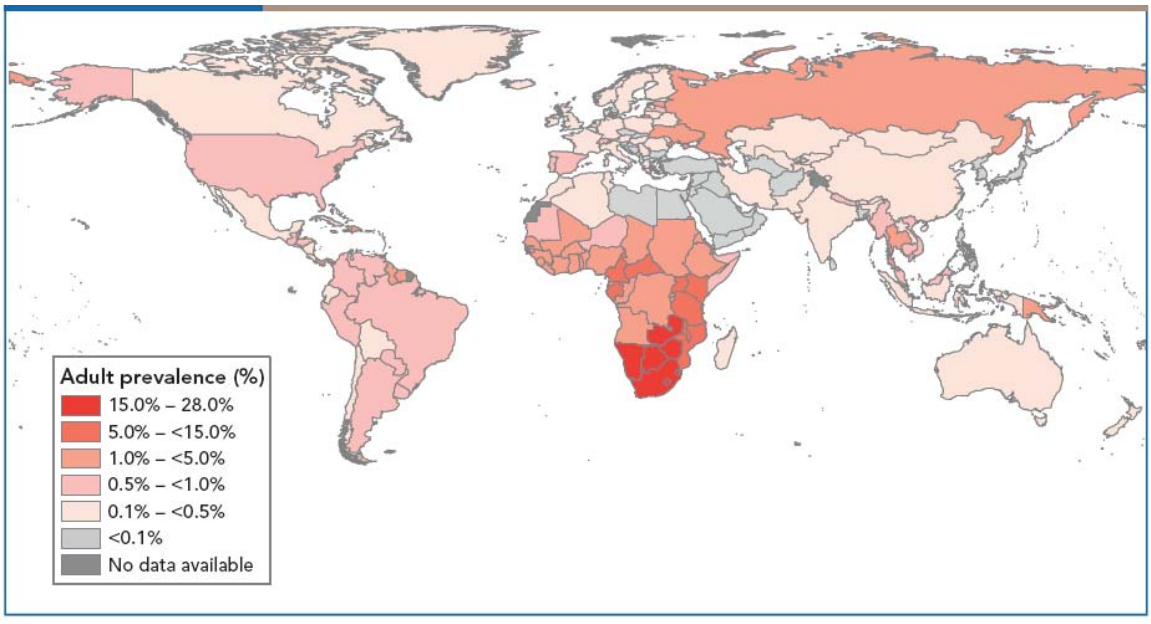
b. What are the characteristics of a concentrated epidemic?

c. In generalised epidemics, do decreases in HIV prevalence occur first in high-risk groups or in the general population?

More on epidemic states

Figure 1.1 shows the state of the HIV epidemic worldwide *(2008 UNAIDS Report on the Global AIDS Epidemic).*

Figure 1.1. State of the HIV epidemic, 2007.



Discussing the figure

Looking at Figure 1.1, on the previous page, answer the following questions:

a. Which countries have the lowest prevalence of HIV?

b. What might explain the differences in HIV prevalence between countries?

HIV prevalence among various high-risk groups

Surveillance in populations at increased risk has varied from country to country. Most countries have been successful in gathering HIV surveillance data from SWs and patients in STI clinics. Several countries have been able to survey MSM, IDUs, prisoners, migrant populations, and uniformed personnel. Examples of surveillance methods are shown below, and examples of the specific groups surveyed are shown in Units 2 through 9 of this module.

Sampling Methods

Conventional sampling techniques

Various sampling methods are used to collect data and measure certain characteristics. Table 1.3, on the next page, provides a brief summary of conventional sampling techniques and their advantages and disadvantages. These techniques include *simple random sampling*, *systematic sampling, stratified sampling,* and *cluster sampling.*

More detailed descriptions of these methods can be found in the Surveillance of HIV Risk Behaviours Module. This surveillance training module can be accessed here:
http://globalhealthsciences.ucsf.edu/PPHG/surveillance/surv_modules.html

Table 1.3. Summary of conventional sampling techniques.

Sampling Technique	Steps	Advantages	Disadvantages
Simple random	1. Construct *sample frame* for survey population 2. Select people randomly from sample frame using *random numbers table* or *lottery draw*	1. Concept is easy to understand and analyse	1. Requires sample frame of entire *target population* 2. Difficult to carry out if sample is geographically dispersed 3. Using random number/lottery is time consuming
Systematic	1. Create a list of the target population 2. Calculate *sampling interval* (SI) 3. Select random start between 1 and SI and select that person 4. Add SI to random start and select person, and so on.	1. Random numbers or lottery not required 2. Easy to analyse	1. Requires sample frame of entire target population 2. Difficult to carry out if sample is geographically dispersed
Stratified	1. Define the *strata* and construct a sample frame for each stratum 2. Take a simple or systematic sample from each stratum 3. Calculate *indicator* estimates for each stratum and for population	1. Produces unbiased estimates of indicators for the strata 2. Can increase precision of indicator estimates	1. Requires sample frame of entire survey population 2. Difficult to carry out if sample is geographically dispersed 3. Requires sample large enough to make precise estimates for each stratum 4. Population estimates require *weighting*

Table 1.3. Summary of conventional sampling techniques, continued.

Sampling Technique	Steps	Advantages	Disadvantages
Cluster: *Probability proportional to size (PPS)* or *equal probability sampling*	1. Construct sample frame of clusters 2. Calculate SI, select random start between 1 and SI 3. Select cluster whose cumulative size contains the random start 4. Add SI to random start and select cluster 5. Sample equal numbers of people from selected clusters	1. Only need sample frame of clusters and individuals in selected clusters 2. Sample concentrated in geographical areas	1. Decreases precision of estimates, thus requiring larger sample size 2. Size of clusters required prior to sampling
Cluster: Equal probability, fixed cluster size	1. Construct sample frame of clusters 2. Select clusters using simple or systematic sampling 3. Sample equal numbers of people from selected clusters	1. Only need sample frame of clusters and individuals in selected clusters 2. Sample is concentrated in geographical areas 3. Do not need cluster sizes before sampling	1. Decreases precision of estimates, thus requiring larger sample size 2. Weighted analysis required for unbiased estimates 3. Size of clusters required for weighted analysis

Table 1.3. Summary of conventional sampling techniques, continued.

Sampling Technique	Steps	Advantages	Disadvantages
Cluster: Equal probability, proportional cluster size	1. Construct sample frame of clusters 2. Select cluster using simple or systematic sampling 3. Sample equal proportions of people per cluster	1. Only need sample frame of clusters and individuals in selected clusters 2. Sample is concentrated in geographical areas	1. Decreases precision of estimates, thus requiring larger sample size 2. Size of clusters required for proportional sampling 3. Sample size, thus precision of estimates, unpredictable

Discussing the table

Looking at Table 1.3, above and on the previous pages, answer the following questions:

a. What are the advantages to using a systematic sampling method?

b. What are the steps to take when using a cluster sampling method: equal probability, fixed cluster-size?

c. What is the disadvantage of using the stratified sampling method when it comes to making population estimates?

Newer sampling methods

Two new sampling methods combine the techniques of *probability sampling* and *non-probability sampling* to help us identify samples that are representative and from which results can be generalised. These are:

- *respondent-driven sampling* (RDS)
- *time-location sampling* (TLS).

RDS and TLS are ideally suited for surveys of high-risk groups, especially those that are harder to find.

Respondent-driven sampling

Recently, researchers have become interested in RDS. Here are the key elements of this method:

- It is a variant of chain-referral methodology.
- It is designed to sample hard-to-reach populations.
- Populations to be sampled using RDS must be connected through social networks (IDUs have excellent social networks since they have to buy drugs from other IDUs and often share or inject with other IDUs; MSM form strong social networks since they have sex and socialize with other MSM).
- It uses several recruitment waves. The first wave is non-randomly selected subjects. After several waves, a sample is obtained that is independent of the first wave.
- It reduces biases associated with chain-referral methods by using a dual system of structured incentives in which peers recruit their peers.
- Collection of personal network size information is critical for analysis of RDS data.

How RDS works

RDS uses two types of structured incentives:

- a reward for being interviewed
- a reward for recruiting peers to be interviewed.

RDS recruitment steps

Once the preliminary steps of planning meetings, obtaining clearance for research on human subjects (ethics review*), and formative research steps are complete, the RDS recruitment steps are as follows:

1. Researchers select a location accessible to the target population. They ensure that the site is discreet and will not attract undue governmental or community concern.

***** See page 35 for ethical considerations related to human subjects research. For further discussion of these issues, refer to the Surveillance of HIV Risk Behaviours Module. This surveillance training module can be accessed here: http://globalhealthsciences.ucsf.edu/PPHG/surveillance/surv_modules.html

2. Based on pre-existing contact with the study group, researchers recruit a handful of participants who serve as the *seeds* (initial study participants) from the target population. Most studies begin with six to 12 seeds depending on the sample size to be reached. Seeds need not be selected randomly, but a diverse selection of seeds may help improve the sample outcome.

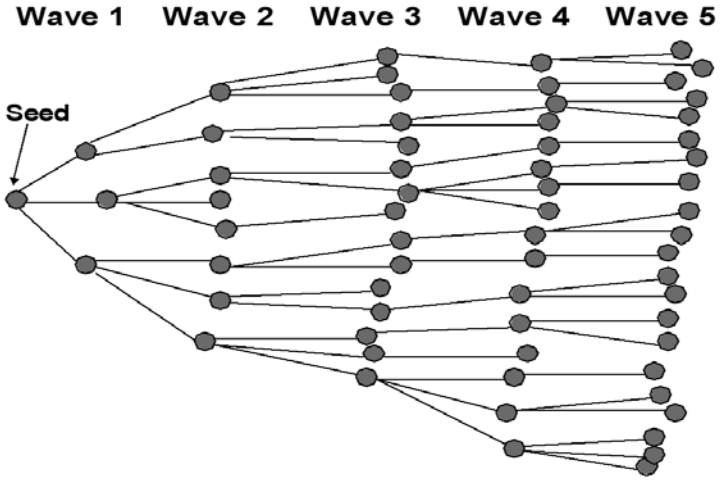
3. Seeds receive an incentive for completing the interview (primary incentive) and another incentive for recruiting their peers to participate in the study (secondary incentive).

4. Once the seeds are interviewed and receive a primary incentive, they are provided with a set number (usually three) of recruitment *coupons* to use in recruiting their peers (other target population members who they know and are similar to them) to be interviewed.

5. When a seed uses a recruitment coupon to select a peer from his or her network and that peer completes an interview and receives a primary incentive, the first wave is formed. The seed receives a secondary incentive for each successful recruit.

6. When the first wave peers recruits their peers and those peers completes an interview, the second wave is formed. Wave peers receive the same dual incentive as the seeds. Note that the initial seeds are not included as a wave. Figure 1.2, a graphic of a sample study with only one seed, shows what may happen as each wave progresses.

Figure 1.2. Seed and five waves in a sample RDS study.



Sampling usually ends when a minimum target sample size has been reached and the research traits of the sample have reached a stable composition.

A more detailed description of the methods and statistical tests used in RDS can be found at www.respondentdrivensampling.org.

Time-location sampling

TLS combines the methods of targeted sampling and cluster sampling to produce a probability sample. The TLS method is like conventional cluster sampling, but it solves the problem of everyone in the target population not being in the same place at the same time. It solves this problem because clusters are defined by location and time. This method requires extensive ethnographic mapping to prepare a sampling frame that reflects the variety in time periods, locations of behaviours, and number of group members.

Time-location sampling:

- samples hard-to-reach populations
- recognises that hard-to-reach populations tend to gather in certain areas
- takes a random sample from public venues
- finds geographically concentrated populations
- uses *formative assessment* and *enumeration* to find the target population's *hotspots*.

How TLS works

TLS uses the fact that some hidden populations tend to gather at certain types of locations. As an example:

- SWs often gather at brothels, massage parlours, and street corners
- MSM may gather in bars, parks, and other meeting areas
- IDUs tend to congregate at injecting locations, such as parks and graveyards or under bridges.

TLS lessons learned

As an effective method to recruit hard-to-reach populations, TLS has been applied to a variety of international settings. The most pronounced *bias* in TLS is that only the more visible "hidden" populations are reached; however, bias can be reduced by including more venues and time-frames.

TLS methods

There are four stages of the TLS method:

Step 1: Prepare for TLS
Staff prepare for sampling by reviewing scientific and prevention literature, searching local newspapers, and interviewing persons who are knowledgeable about the target population and HIV prevention services.

The goals of these investigations are to construct a list of venues identified as used by the target population, to identify potential difficulties in sampling, and to help construct prevention and service measures to include as part of the questionnaire.

Step 2: Construct the sampling frame
Staff will use the list of venues to construct monthly sampling frames of venues and day-time periods (four-hour blocks of time that would yield at least eight participants). Standardized enumerations of eligible participants are used to help select which venues and day-time periods are included in the sampling frames.

Step 3: Construct the sampling plan
To make the sampling plan, the venues first are randomly selected from sampling frames. Second, the day-time periods are randomly selected for each venue. Random selection is essential to creating a probability sample.

Step 4: Sample the participants
The final stage of TLS is done at the venue when staff enumerate, approach, and interview members of the target population to find eligible people who would like to participate in the study.

Comparing RDS and TLS

See sampling steps and a comparison of TLS and RDS in Table 1.4.

Table 1.4. Comparing time-location and respondent-driven sampling.

Time-Location Sampling (TLS)	Respondent-Driven Sampling (RDS)
Steps: ▪ Write the procedures and calculate the required sample size ▪ Conduct formative assessment ▪ Identify *clusters* using ethnographic mapping. A cluster is any aggregate of the population of interest (for example, departments, villages, health facilities). ▪ Construct a sample frame of clusters. Define clusters by both location and time if the population is floating ▪ Select clusters and individuals in clusters using equal probability sampling	Steps: ▪ Write the procedures and calculate the required sample size ▪ Conduct formative assessment. ▪ Start with initial contacts or seeds who are surveyed and who then become recruiters ▪ Each recruiter invites up to three people from their own high-risk group to be interviewed ▪ The new recruits become the recruiters ▪ Several recruitment waves occur
Requirements: ▪ Extensive mapping and ethnographic work is needed ▪ Need to create a sample frame of location and time (clusters) and individuals in selected clusters ▪ Need co-ordination with *gatekeepers*, such as bar owners and pimps. ▪ The interviewers should be able to identify and approach members of the target population ▪ Adjusting the estimates during data analysis is important because estimating cluster size in advance is difficult	Requirements: ▪ The target population must be in networks ▪ Need to keep track of links between recruiters (who are members of the target population) and recruits ▪ The size of group members' networks must be documented ▪ Sample must reach *equilibrium* ▪ Special statistical software must be used to adjust the final data. The most commonly used software is RDSAT

Table 1.4. Comparing time-location and respondent-driven sampling, continued

Time-Location Sampling (TLS)	Respondent-Driven Sampling (RDS)
Special considerations: ▪ TLS lets us do a probability sample of populations whose members go to certain venues and sites ▪ It is difficult to maintain randomness while selecting respondents within clusters ▪ Clusters and sites can close quickly ▪ Samples can be concentrated in geographical areas	Special considerations: ▪ Can reach sub-groups who do not visit certain venues or clinics ▪ If conducted correctly, can provide unbiased estimates ▪ There is much less need for ethnographic mapping. Field operations can be done in office settings ▪ Because the target population does the recruiting, it still works when it is hard to identify members of the target population

Discussing the table

Looking at Table 1.4, answer the following questions:

a. How are clusters identified in TLS?

b. At the beginning of a study using RDS, what is the role of new recruits?

c. What are the special considerations when using TLS?

Choosing the sampling approach

You should assess sampling options for each high-risk group that you will sample. Answering the following questions can help guide the selection of sampling strategies:

- Do group members gather in high proportions in accessible locations or sites?
- Is it possible to make a list of all group members associated with each site?
- Are all groups on the list easily accessible during data collection? This refers not only to the groups that happened to be present at a site.

Detailed information on the sampling and survey methods used to do surveillance among high-risk groups is provided in the module entitled "Surveillance of High-Risk Behaviours." Detailed information on the survey methods applicable to behavioural and biological surveillance of high-risk groups is presented later in this module.

Calculating sample size

Annex 1.1: Formula for Sample Size Calculation provides pre-calculated sample-size estimates for a range of possible scenarios in behavioural and biological surveillance.

In many situations you may not know the size of your target population. Methods on how to estimate the size of a specific population are described in Annex 1.2: Estimating the Size of your Target Population.

Measures and Indicators

Indicators for *behavioural surveillance* measure behaviours that are essential to the spread of HIV and that are targeted by HIV prevention programmes. These are:

- behaviours that increase the chance that an uninfected person will come into contact with an infected person (for example, having more and different types of sexual partners)
- behaviours that increase the chance that HIV will be transmitted if contact with an HIV-infected person occurs (for example, sharing needles or not using condoms).

You should choose indicators for surveying high-risk groups based on the data your country needs. Essential indicators for SWs, IDUs, and the general population are shown in Table 1.5, on the next page.

Further information and the specific wording and definitions of questions and indicators that are used internationally can be found in the module entitled "Surveillance of High-Risk Behaviours" and at the following websites:

- *United Nations General Assembly Special Session on HIV/AIDS* (UNGASS) has developed a set of core indicators. Monitoring the Declaration of Commitment on HIV/AIDS Guidelines on Construction of Core Indicators is available online at: http://www.ua2010.org/index.php/en/UNGASS/Meeting-UNGASS-Targets/UNGASS-Core-Indicators

- Family Health International (FHI) publishes guidelines for repeated behavioural surveys in populations at risk of HIV, including indicators that are necessary in the spread of HIV among high-risk groups. These guidelines are available online at: http://www.fhi.org (English)

- The HIV/AIDS Survey Indicators Database of MEASURES DHS includes applicable health indicators that are used to evaluate attitudes and behaviours relative to the health risks measured by HIV and STI prevalence surveys. These indicators are available at: http://www.measuredhs.com/hivdata/ind_tbl.cfm.

- The UNAIDS Indicator Registry, developed by the CRIS Unit in collaboration with monitoring and evaluation experts, is a facility for harmonising and publishing indicator definitions and sets on the internet. Further information is available at: http://www.unaids.org/en/KnowledgeCentre/HIVData/CRIS/CRIS_Data.asp or www.indicatorregistry.org.

Measures and indicators, continued

- PEPFAR Next Generation Indicators were developed to meet the needs of PEPFAR to demonstrate progress in the fight against HIV/AIDS. Taken together these indicators promote responsible program monitoring across and within PEPFAR funded technical areas. The PEPFAR Next Generation Indicators Reference Guide is available at: http://www.pepfar.gov/documents/organization/81097.pdf

Indicators recommended by international bodies may not discuss all behaviours relevant to your area. Some questions will be for local use only (for example, exposure to specific prevention programmes or assessing particular risky practises). The formative assessment phase should be used to determine the questions relevant to the epidemic in your area. In addition, the wording of the indicators must be translated and field-tested in your local languages.

Indicators for the general population also can be modified and used for some high-risk groups, such as migrants, uniformed personnel, and prisoners. In addition, it is usual for data to be collected on background information and on factors such as alcohol or drug use that promote high-risk behaviours. In this way, indicators can be compared across different socio-demographic groups.

Table 1.5. Essential indicators for behavioural surveillance in injecting drug users, sex workers, and men who have sex with men.

Injecting drug users (IDUs)	Sex workers (SWs)	Men who have sex with men (MSM)
▪ proportion who shared needles last time ▪ proportion who did not use clean needles consistently in past week (or other time period) ▪ proportion who shared drugs ▪ proportion who used condoms	▪ proportion who used condoms last time and consistently with clients ▪ proportion who injected drugs in past year	▪ proportion who used a condom the last time they had anal sex with a male partner ▪ proportion who have had anal sex with more than one male partner in the past year

Discussing the table

Looking at Table 1.5, on the previous page, answer the following questions:

a. What is one common indicator for behavioural surveillance found in all three populations?

b. What is the indicator, besides condom use, listed for behavioural surveillance among SWs?

Further information on the behavioural measures used in surveillance of high-risk groups is provided later in this module and in the module entitled "Surveillance of High-Risk Behaviours."

Deciding whether to test

Most behavioural surveys can be handled in two ways: with or without biological sampling. Your choice depends on the objective of your survey.

Behavioural surveillance without biological sampling is a simple and inexpensive way to discover and explain trends in sexual and injecting behaviour in a sub-population.

In addition, behavioural surveillance with biological sampling lets us link data on socio-demographics and sexual behaviour with HIV/STI results from the same population. This link further validates self-reported sexual and injecting behaviour and estimates prevalence trends among hard-to-reach populations.

Questions to ask when planning biological sampling are:

- is there adequate space at the site for counselling and testing?
- are there enough supplies and personnel for collecting specimens?
- what is the organisation in laboratory capabilities, transportation, and storing specimens?
- how do we make sure we take care of ethical matters: maintaining confidentiality, approval by ethical review board, adaptation of consent form?
- is there a bias in the refusal rate?

Whether biological sampling is incorporated in the study depends on how you will use the information.

Information on the different options for HIV testing is provided in Annex 1.3: Choosing an HIV Test.

Biological measures

There are a number of choices to make about which biological measures to use in surveys of high-risk groups. First is the choice of which infections to study. Choices include HIV, which is almost always included, and other infections that are markers of behaviours associated with HIV transmission. The following table summarises this information.

Table 1.6. Testing for STIs and blood-borne infections based on type of transmission.

Type of transmission	Infections to test for
Sexual	▪ *syphilis* ▪ *gonorrhoea* ▪ *Chlamydia* ▪ *herpes simplex virus type 2* (HSV-2) ▪ *hepatitis B virus* (HBV) ▪ *trichomoniasis* ▪ *human papilloma virus* (HPV) ▪ *Haemophilus ducreyi* (chancroid) ▪ *Treponema pallidum*
Parenteral (blood-borne)	▪ *hepatitis C virus* (HCV) ▪ *syphilis*

Discussing the table

Looking at Table 1.6, answer the following questions:

a. Which infection is characterised by both sexual and *parenteral* (blood-borne) transmission?

b. What type of transmission characterises *T. pallidum*?

The survey setting is important. If there is the possibility of only a single visit, rapid testing for HIV is essential. If there are problems with drawing blood, you can test saliva for HIV. This is useful if certain populations have difficult venous access (as with IDUs) or if patients fear needles.

Later in this unit, we will review the different biological measures and their advantages and disadvantages in high-risk and hard-to-reach groups.

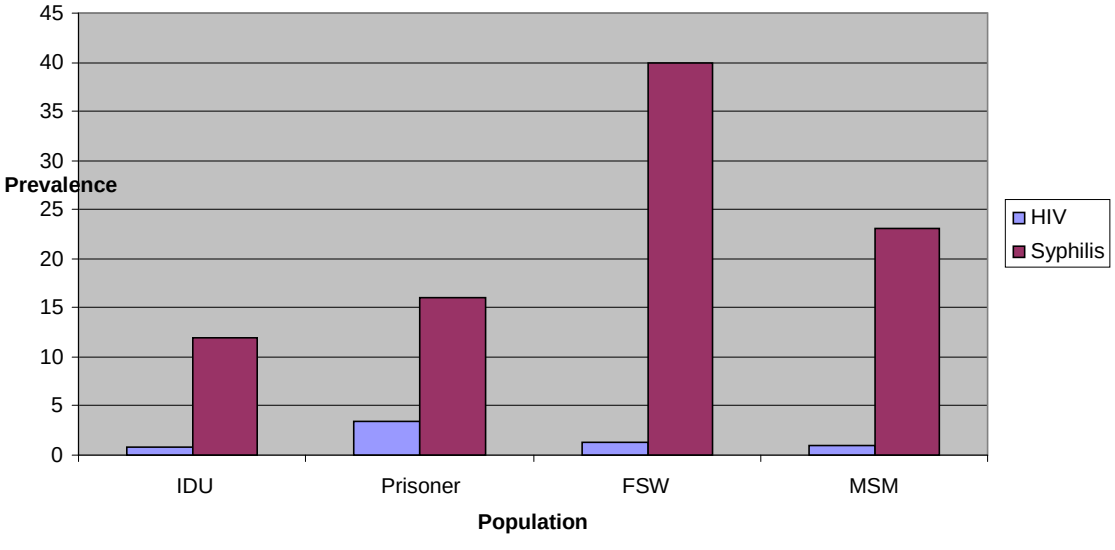
Sexually transmitted infections

In high-risk groups, rates of acute STIs often are used as a proxy for behaviours that could transmit HIV. Persons whose sexual risk is high enough to acquire an STI also may acquire HIV if they are exposed to it. Also, STIs often are more common than HIV, making studies more efficient than HIV prevalence surveys. The STIs can serve as an early warning sign for HIV because they often are present in a population before HIV enters it. In practise, HIV cohort studies are expensive and complicated and measures of HIV *incidence* are not widely available. Therefore, monitoring and evaluating the success of HIV prevention programmes often relies on incidence and prevalence data on STIs.

Examples of populations in which STIs serve as a good proxy for behavioural risk of HIV infection are:

- SWs
- patients of STI clinics
- MSM
- mobile populations, such as truck drivers, fishermen, and migrant labourers
- *prisoners*
- uniformed personnel.

Figure 1.3. HIV and Syphilis Prevalence from sentinel surveys in Bishkek and Osh, Kyrgyzstan (2005)



Source: Ministry of Health Kyrgyzstan, 2007; Republic AIDS Centre, 2005, UNAIDS

Discussing the table

Looking at Figure 1.3, on the previous page, answer the following question:

a. What do the high levels of syphilis found among SWs, MSM, prisoners, and IDUs suggest about HIV transmission?

Rates of STIs also can be used to evaluate HIV prevention programmes. Both ulcerative STIs (syphilis, chancroid, HSV-2) and inflammatory STIs (gonorrhoea, Chlamydia) can increase the risk of acquiring and transmitting HIV infection. Therefore, controlling STIs in high-risk groups and in groups with high incidence of HIV is an important HIV prevention strategy. The success of these STI control programmes is evaluated primarily by examining the incidence and prevalence of STIs.

Testing for STIs

STIs that are most frequently measured are:

- syphilis
- gonorrhoea
- Chlamydia
- HSV-2
- HBV
- trichomoniasis
- HPV.

Depending on the organism, positive test results can mean either recent infection (indicating recent high-risk sex) or past infection (indicating past high-risk sex). Because some STIs are frequently asymptomatic, their true prevalence cannot be determined by the presence of symptoms alone. For Chlamydia and gonorrhoea, testing is necessary, especially in women.

Recent high-risk sex can be determined by a positive test for:

- gonorrhoea
- Chlamydia
- syphilis (high-titre syphilis means new infection, low titres mean past infection)
- trichomoniasis.

Past high-risk sex is usually determined by a positive test for:

- syphilis (low titre)
- HSV-2
- hepatitis B (immunoglobulin G).

Testing for STIs, continued

Tests for syphilis, HSV-2, and HBV require blood samples. Antibody tests for chancroid can be done, but are not widely available. Gonorrhoea and Chlamydia can be detected in urine or genital swabs (urethral swabs in men, rarely, and endocervical or vaginal swabs in women). It is easy to collect urine to detect gonorrhoea and Chlamydia, so these infections often are measured in hard-to-reach groups.

High-titre syphilis (a titre of 1:8 or higher) is a very good marker of recent sexual risk-taking. If any of the bacterial infections (syphilis, gonorrhoea or Chlamydia) are detected, there is an ethical obligation to treat the infection. Therefore, studies in which treatable bacterial STIs are measured must treat participants and manage their sexual contacts.

Parenterally transmitted infections

In areas where there is suspected overlap between SWs and IDUs, you should consider including testing for parenterally transmitted infections. HCV is the blood-borne infection most typically measured.

Presence of HCV can be measured using a variety of laboratory tests, but most often used is a simple *enzyme immunoassay* (EIA). As with HIV, antibodies for HCV will be present for long periods of time—often decades—in most patients. Although EIAs can detect more than 95% of chronically infected patients, they can detect only 50% to 70% of acute infections. For this reason, a *recombinant immunoblot assay* (RIBA) often is used as an extra test for HCV.

In addition, it is possible to screen for liver damage—an indirect marker of current or past hepatitis—using liver function tests. The most common of these tests is alanine-leucine transferase (ALT). Less commonly used is aspartate aminotransferase (AST). Note that ALT levels can be elevated in persons with alcoholic damage to the liver, although the damage is seen more prominently using AST levels.

It should be noted that in some countries, the re-use of needles in medical settings and in piercing and scarification practises contribute to parenteral transmission of HCV.

Additionally, in parts of Egypt, the country with the highest prevalence of HCV in the world, the virus is endemic due to the unintended consequences of a governmental effort in the 1970s to combat schistosomiasis using HCV-contaminated needles. In areas where HCV is endemic, such as Egypt's Nile Delta region, the virus probably is not a good indicator for injection drug use.

Ethical Considerations

High-risk groups often are difficult to reach and are not included in regular surveillance activities. Because of this, there can be large gaps in our knowledge about HIV in a country or district and how HIV is spread. Additionally, surveillance data can contribute to advocacy for improved care and treatment for these vulnerable populations.

You should consider whether your proposed surveillance activity would constitute human subjects research, thus requiring Institutional Review Board (IRB) or ethical review from participating institutions (local, implementing, funding institutions) before implementation.

Potential harms

Many MARPs are marginalised, and their behaviour is illegal in most countries. MARPs that have legitimate fears of surveillance and reactions of the larger society include the following:

- SWs
- IDUs
- MSM
- refugees and internally displaced persons
- prisoners.

Some level of risk exists for all MARPs if their status is disclosed. A list of potential harms from surveillance is shown in Table 1.7.

Table 1.7. Potential harms caused by HIV and behavioural surveillance in MARPs.

Type of harm	Examples
Physical	public attack, abuse, loss of healthcare services
Psychological	depression, suicide
Legal	arrest, prosecution
Social	negative reaction of family, workplace discrimination, loss of employment, isolation

Discussing the table

Looking at Table 1.7, answer the following questions.

a. What are two potential harms facing IDUs who participate in HIV surveillance activities?

b. What are two potential harms facing SWs who participate in HIV surveillance activities?

WHO ethical guidelines

In 2003, the WHO published a set of guidelines specifically directed toward ethical considerations involved in second-generation surveillance (available at www.who.int/hiv/pub/epidemiology/sgs_ethical). These guidelines provide an overview of medical ethics, the ethics of epidemiological research, and the ethics of surveillance. Other issues addressed are:

- data collection in behavioural surveillance and sero-surveillance
- consent to participate in studies
- use and dissemination of data
- participants' right to access test results.

Confidentiality

Confidentiality protects participants from difficulties that may arise from involvement in a study or survey. If a person's HIV infection becomes known, he or she may suffer discrimination or stigma and even may be subject to criminal charges. Be aware of any part of your country's laws that may make participation difficult. These may include:

- laws about age of legal adulthood, including when adolescents can consent to participate in studies
- laws prohibiting sex work or sex work for people under a certain age
- laws prohibiting men to have sex with men
- laws prohibiting injection drug use
- laws requiring reporting people with HIV infection
- laws that protect study results from legal proceedings.

People asked to participate in a survey or study should understand potential threats to their confidentiality. They also should understand the steps that the investigators will take to minimise the risks. Explaining these issues to participants is part of the *informed consent* process.

Approaches to HIV testing

In doing surveillance there are several approaches to testing people for HIV. The four main considerations that may affect *participation bias* in HIV testing are listed in the following questions:

- Is testing *anonymous* or *confidential*?
- Are specimens linked or not linked to identifying information about a patient?
- Does the patient consent to be tested?
- Are the test results given to the patient?

Linking

Linking refers to whether a person's name, identifying information, or personal code is associated with HIV test results. Linking can include personal identifiers, such as birth date or a name or both or it can include only demographic and behavioural information that is attached to HIV test results. The identifying information is recorded on the container for the sample of blood drawn for the HIV test and then is attached to the HIV test result. The identifier is used to return HIV results to participants.

If test results are returned to participants, activities should include:

- informed consent
- pre- and post-test counselling
- confirmatory testing
- referral to needed healthcare and other services.

Prior to analysing or sharing data, it is important that you remove all personal identifying information, such as the patient's name, address, and government-issued identification number.

Unlinked anonymous testing (UAT) refers to removing identifying information or the means to link HIV test results to participants. Although unlinking HIV test results from someone's personal identifying information makes certain of confidentiality and reduces participation bias, it prevents post-test counselling and returning results to the people tested. This method is used primarily in clinic settings with leftover blood from routine testing.

Informed consent

Surveys and studies in high-risk groups usually require the formal informed consent of the people participating. This means disclosing information that will be important to a person's decision whether to participate.

Whenever informed consent is obtained, it is important to watch for participation bias. It may be useful to add a check box on consent forms to indicate people who choose not to participate so that you can evaluate participation bias. If this is not possible, you can use other ways to collect information on non-participants during data collection.

Consent forms and surrogate consent

Written consent forms are generally needed to document that informed consent has occurred. The appropriate reading level for consent forms is eighth grade or lower. When the study is anonymous and the most substantial risk to participants is loss of confidentiality or when literacy is low, a verbal consent form may be utilized which the participant does not need to sign. Verbal consent needs to be documented, and participants should be offered an information sheet with the elements covered in informed consent.

United States Federal regulations specify requirements for informed consent. All consent documents must address three general principles: voluntariness, comprehension, and coercion. Federal regulations also list eight required elements of informed consent. These are:

1. Purpose and Procedures
2. Risks
3. Benefits
4. Alternatives
5. Confidentiality
6. Compensation or Treatment for Injury
7. Persons to Contact
8. Voluntary Participation, Refusal, and Withdrawal

For a description of these required elements, see Annex 1.4. For specific guidance on developing consent forms for CDC-related research, refer to *Consent for CDC Research: A Reference for Developing Consent Forms and Oral Scripts*. It can be accessed at: http://casr.ou.edu/hiv/consent_letters.pdf

Examples of written and verbal consent forms are included in Annex 1.5: Examples of Verbal and Written Consent to Participate in a Survey. You should check with your institution's IRB or human subjects research office for specific requirements and guidelines on the format and content of your consent form.

When people are not capable of giving written or verbal informed consent, surrogate consent can be obtained. Examples of this are when a parent gives consent for a child or a guardian gives consent for an adult with severe illness. Countries also may have laws about the age at which an adolescent can participate in research without their parents' consent and

Consent forms and surrogate consent, continued

about who may provide surrogate consent for orphans or street children. You should familiarise yourself with these laws in your country before starting the survey.

Although potential participants in surveillance and research activities are informed that participation is entirely voluntary, some groups may feel coerced into participation. Prisoners and lower-ranking members of uniformed services are especially vulnerable to the belief that if they do not participate, they will be punished. In these situations, you must make sure that effective communication and understanding is involved in the informed consent process.

Additionally, in some countries a woman may not legally participate in a surveillance activity without the consent of her husband. Although a husband's consent may be required, it does not take the place of the woman's personal consent. In this case, the consent of both the husband and the participant may be required.

Further information on the ethical issues related to surveillance of high-risk groups is provided in Units 2 through 9 in this module.

Data management, analysis, and use

A data management element in your protocol should be designed to secure all data in order to protect the confidentiality of survey participants. Data management procedures include limiting access to any identifying information to authorised survey personnel, keeping survey materials (both paper-based and electronic), in a locked, limited-access room or computer, and requiring all staff to sign confidentiality forms and undergo training in research ethics.

Many sampling methods utilized in surveillance of most-at-risk populations require specialized analyses and techniques. You should involve a statistician in the design and implementation of surveillance activities in order to ensure that the necessary information for data analysis is captured. Similarly, you should work with a statistician during the data analysis phase to confirm that it is done correctly.

Data obtained from MARPs surveillance can be used for strategic planning of intervention portfolios, resource allocation, program monitoring and evaluation, and advocacy.

For more information on issues of data management, data analysis, and data use, refer to the Surveillance of HIV Risk Behaviours Module. This surveillance training module can be accessed here: http://globalhealthsciences.ucsf.edu/PPHG/surveillance/surv_modules.html

Summary

An important part of behavioural surveillance and sero-surveillance is determining the prevalence of HIV in groups that are at high risk of acquiring and transmitting HIV. Surveillance of high-risk groups is particularly important at the beginning of an HIV epidemic, as the first infections often appear in these groups. Surveillance data must be given to the populations and agencies that can use them.

Populations at increased risk include SWs, IDUs, MSM, mobile populations, street children, prisoners, and uniformed personnel. Many populations at increased risk are also vulnerable to a variety of social factors, and, as a result, surveillance and special studies in these groups raise several ethical issues. There are a number of conventional probability sampling methods that can be used. Because many populations at increased risk also are hard to reach, RDS and TLS methods are ideal for surveys of these groups.

Exercises

Warm-up review

Take a few minutes now to look back on your answers for the warm-up questions at the beginning of this unit. Make any changes you want to make. We will discuss the questions and answers in a few minutes.

Small group discussion

Get into small groups to discuss these questions:

1. In your country, what populations are most at risk of acquiring HIV?

2. Does your country conduct HIV surveillance among these populations? How frequently?

Annex 1.1. Formula for Sample Size Calculation

The sample size needed to conduct behavioural and biological surveys can be based on the number of participants needed in each round (or year) to detect a change in the proportion of an indicator from one round to the next. As an example, you would like enough sex workers (SWs) in your survey rounds to show that condom use at last paid sex increased from 20% in the year 2006 to 30% in 2007.

The general formula for the needed sample size (n) is:

$$n = \frac{D\left[Z_{1-\alpha}\sqrt{2P(1-P)} + Z_{1-\beta}\sqrt{P_1(1-P_1)+P_2(1-P_2)}\right]^2}{(P_2-P_1)^2}$$

Where:

n	=	Sample size required per survey round (year)
D	=	Design effect (see below)
$Z_{1-\alpha}$	=	The z score for the desired confidence level, usually 1.96 for 95%
$Z_{1-\beta}$	=	The z score for the desired power, usually 0.83 for 80%
P_1	=	The proportion of the sample reporting indicator in year 1
P_2	=	The proportion of the sample reporting indicator in year 2
P	=	$(P_1 + P_2)/2$

Choosing the values of these numbers is based on the following considerations:

D design effect: The design effect can be considered a correction factor for how much a cluster sample differs from a simple random sample. Effectively, the design effect multiplies the sample size by a factor of D. The design effect accounts for the similarities people have when they are sampled within the same cluster. Female SWs within a particular brothel, for example, may be similar with respect to condom use because of the social norms, condom availability, or intervention programmes of that particular brothel. Choosing a design effect is difficult without prior survey data. Design effects from 1 (that is, none) to 2 (moderate) cover a

Annex 1.1. Formula for sample size calculation, continued

typical range. For RDS surveys, a design effect of 2.0 is recommended. For cluster sampling and TLS, a design effect of 2.0 is also recommended. ***The bigger the D, the larger the sample size needed.***

P_1 and P_2: P_1 and P_2 are the measures of interest for which you wish to see a change between survey rounds. You may wish, for example, to show that condom use at last paid sex for SWs increased from 20% in 2006 (P_1) to 30% or greater in 2007 (P_2). P_1 is usually based on previous surveys in the same or similar population, or an educated guess at what the level will be. P_2 is ideally set at the goal you would like to achieve (for example, a 10% or greater increase in condom use). In practise, it is usually set at the smallest change you think is meaningful; for example, a 10% increase in condom use would be considered a meaningful improvement, whereas a 1% increase would not be considered meaningful. ***The smaller the change you wish to detect, the larger the sample size you will need. Also, the closer P_1 and P_2 are to 50%, the larger the sample size you will need.***

$Z_{1-\alpha}$: The $Z_{1-\alpha}$ score is a statistic that corresponds to the level of significance desired. Usually, a significance level of 0.05 (or equivalently, a 95% confidence level) is selected and corresponds to a value of 1.96. This value is used when the change in the indicator might be either up (an increase) or down (a decrease) from year to year (a "two-tailed" statistic). ***The smaller the significance level (that is, the higher the confidence level), the larger the sample size you will need.***

$Z_{1-\beta}$: The $Z_{1-\beta}$ score is a statistic that corresponds to the power desired. Usually, 80% power is selected and corresponds to a value of 0.83. This value is used when the change in the indicator might be either up (an increase) or down (a decrease) from year to year (a "two-tailed" statistic). ***The higher the power, the larger the sample size you will need.***

Table 1, on the next page, provides pre-calculated sample size estimates for a range of possible scenarios in behavioural and sero-surveillance.

Annex 1.1. Formula for sample size calculation, continued

Table 1. Sample size needed per survey wave to detect a change in the proportion of an indicator between survey waves, using a 95% confidence level, 80% power, and a design effect of 2.0.

Indicator level in wave 1 (P1)	Indicator level in wave 2 (P2)	Sample size needed each wave with a design effect of 2.0
.10	.20	395
.10	.25	197
.20	.30	581
.20	.35	274
.30	.40	706
.30	.45	322
.40	.50	768
.40	.55	343
.50	.60	768
.50	.65	336
.60	.70	706
.60	.75	301
.70	.80	581
.70	.85	239
.80	.90	395
.80	.95	149

Annex 1.2: Estimating the Size of your Target Population

Introduction

Although countries are able to identify populations most at risk for HIV infection, few are able to accurately estimate the size of these populations.

Estimating the size of your target population may or may not be necessary as part of formative work, but can also be a useful tool to apply during the or in addition to the surveillance. With accurate measures and estimates of the impact and magnitude of HIV, countries can carry out programme activities in order to advocate for most-at-risk populations, plan and implement HIV prevention, care and treatment programmes, and evaluate programmes.

This annex introduces some methods you can use to estimate the size of populations most at risk for HIV infection.

Methods of estimating the size of your target population

Estimation options

Although a variety of methods are available to estimate the size of most-at-risk populations, different methods may be appropriate for different purposes. These methods include:

- census and enumeration methods
- multiplier methods
- capture-recapture methods.

Keep in mind that these methods can be used either alone or in combination.

Although not described in this annex, other methods of estimating the size of most-at-risk populations include:

- adding direct questions to population based surveys
- network scale-up method.

Defining your target population

Regardless of which method you use, you must first define the target population and the geographic location of interest. You may want to estimate the number of persons in Al Rabia, Globa who injected drugs within the past 12 months, for example.

Census and enumeration methods

Census and enumeration methods involve the counting of individuals within your target population.

Census methods

Census methods attempt to count every individual in the target population. An example of this is visiting every brothel in the city and counting the number of individual SWs in each brothel.

Enumeration methods

Enumeration methods are similar to census methods but instead rely on a sampling frame or list. When using enumeration methods, you choose a sample from the list and count only individuals from within the chosen units. You may, for example, select five of the 20 brothels and count all SWs working at those five brothels. The number counted is then scaled up according to the size and structure of the sampling frame.

Multiplier method

The multiplier method is a relatively straightforward way of estimating the size of a specific population. This method relies on having information from two data sources that overlap in a known manner. It can be used with information from two separate population-based survey samples that intersect in some way. The primary challenge when using this method is finding data sources that correspond with each other.

Using the multiplier method requires:

- having good institutional record-keeping
- behavioural surveillance instruments that include questions related to your target population (e.g., number of males in the general population that frequent SWs, number of clients per week per SW).

Multiplier method
Exercise 1:

As the National AIDS Programme manager of Globa, you want to estimate the number of SWs in the country.

The data available are a nationally representative household survey and a behavioural surveillance survey among SWs and their male clients. Information from the household survey suggests that 12% of the 1.45 million adult men in Globa reported visiting an SW in the last year. Behavioural surveillance among the male clients of SWs shows that they go to SWs on average of every two weeks, or 26 times a year. Behavioural surveillance among SWs shows that each SW has sex with clients an average of 11 times a week, but that she goes home to her village (where she does not work) for an average of three weeks per year.

How would you estimate the number of SWs in Globa?

Multiplier method
Exercise 1 solution:

Total number of male clients is the number of men in the sexually active age group times the proportion that say they buy sex:

12% x 1.45 million = 174 000

Total number of commercial sex acts in a year is the number of men who buy sex times the average number of commercial sex acts per client per year:

174 000 x 26 = 4 524 000

Average number of sex acts per SW per year is the average number of sex acts per SW per week times the number of weeks that the SW works:

11 x (52-3) = 539

Because the absolute number of commercial sex acts between the male clients of the SWs and the SWs themselves must be the same, we can calculate the number of SWs from the total number of commercial sex acts divided by the average number of sex acts per SW per year:

4 524 000/539 = 8400

You estimate that there are 8400 SWs in Globa.

Multiplier method
Exercise 2:

As the National AIDS Programme manager of Globa, you want to estimate the number of injection drug users (IDUs) in the country.

The data you have available include data on the injecting habits of IDUs in treatment. All IDUs report injecting heroin and inject on average three times per day, about 0.05 grams per injection.

Unfortunately the total number of injectors in treatment is not known and you do not know of any other data sources. Through consultations with the UN Office on Drugs and Crime (UNODC) office in Globa you learn that only 2% of the heroin coming into the country is being seized by drug enforcement agencies. UNODC provides you with the drug seizure data which show that 39 kilos of heroin were seized in the last year.

Using the above data, how would you estimate the number of IDUs in Globa?

Multiplier method
Exercise 2 solution:

If only 2% of heroin is seized, then:

39 000 x 100/2 = 1 950 000 grams of heroin comes into the country each year

If each injector injects three times per day and 0.05 grams per injection, then each injector injects:

0.05 x 3 x 365 = 54.75 grams of heroin per year

The total number of injectors must therefore be:

1 950 000/54.75 = 35 616

You estimate that there are 35 616 IDUs in Globa.

Capture- Recapture

Capture-recapture is a technique used to estimate the number of persons in a target population. Originally developed by ecologists, the capture-recapture method was designed to estimate the total number of animals in closed populations. According to this methodology, two or more lists containing individuals in common can establish the number of individuals missing from both, thereby estimating the total population of interest.

Assumptions of capture-recapture

Four assumptions must be met in order to provide a valid estimate:

1. the population under study is closed (that is, persons do not migrate in or out of the catchment area)
2. the two sources of data are independent (trap attraction/avoidance)
3. the sources of data are homogenous (that is, all the members in the population should have the same chance to be listed in each data source)
4. individuals can be matched from capture to recapture.

Limitations of capture-recapture

It is rare that the four assumptions of capture-recapture are met in populations most at risk for HIV infection.

In epidemiology, the two sample methods are rarely appropriate due to list dependency and population heterogeneity.

List dependency is defined as when people who are in list 1 (a harm reduction *non-governmental organisation* [NGO]) might be referred by a private methadone clinic (list 2)

Population heterogeneity: People who go to a harm reduction NGO (list 1) might be different (for example, by socio-economic status) than people who go to a private clinic (list 2)

Analyzing three or more sources using a 2x3 table or log-linear model eliminates much of the bias associated with capture-recapture because it eliminates the bias of independence of sources and homogeneity.

Capture-recapture analysis

To complete a capture-recapture analysis, two or more data sets are required. If two data sets are used, 2x2 tables are useful for determining the number of cases not included in either dataset and thus can be used to estimate the total population (Figure 1).

Given that the assumptions stated above hold, estimated population size is given by:

$$N = \frac{MC}{R},$$

Where:

N = Estimate of total population size;
M = Total number of people captured and marked on the first visit;
C = Total number of people captured and marked on the second visit; and
R = Number of people captured on the first visit that were then recaptured on the second visit (i.e., included in both samples).

- The top row includes all the people "captured", or identified, in the first sample
- The first column includes all the people captured in the second sample.
- The total number, N, includes all those in both samples as well as those missed by both samples.

Figure 1: Two-by-two Table for Capture Recapture Analysis

Were they captured in the second sample?

Were they captured in the first sample?	Yes	No	
Yes	R	b	M = R + b
No	c	**x**	

C = R + c N = R + b +c + x

Detailed example of how to use capture-recapture data

A study team is using the capture-recapture method to determine the size of an at-risk population. After mapping the area they wish to study, a member of the team goes to the area to "capture" individuals:

- 50 individuals are marked on the first visit
- 25 of those individuals are recaptured on the second visit the next day.

The field worker concludes that the probability of capturing a previously-marked individual on the second visit is:
R / M = 25 / 50 = 0.50.

The field worker assumes on the second day that all individuals in the actual population, N, have the same capture probability as the recaptured individuals. The field worker thinks on the second visit, "I know that today I recaptured 50% of the people I marked during my first visit. Today I probably also captured 50% of the individuals that I did not mark on my first visit. In fact, today I probably captured 50% of all the individuals present in the study site regardless of whether or not those individuals were marked on my first visit." This can be expressed as:

$$\frac{C}{N} = \frac{R}{M}.$$

You can see, then, how the formula for N, total estimated population size, is derived.

Note: It is also possible to calculate a confidence interval to give a range of error for the estimate of total population size:

$$95\%CI = N \pm 1.96\sqrt{Var(N)}$$

Where Var(N) is calculated as:

$$\frac{MC \bullet (M-R) \bullet (C-R)}{R^3}$$

Capture-recapture Exercise:

The Al Rabia City Department of Public Health has decided to conduct a survey of IDUs in Al Rabia to gather information on the behaviours driving the epidemic among IDUs. Although NGO and police reports indicate that there is a growing IDU population, the Department of Public Health does not know its size.

To estimate the size of this population, the Department of Public Health decides to enlist the support of all harm reduction NGO clinics serving IDUs and all methadone maintenance clinics in the city. After describing the purpose of the surveillance activity and convincing the clinics that the patients' names and information will be kept confidential, the Department of Public Health are given the clinics' intake registers which include the names and birth dates of all the IDUs who sought services from them in the past month.

Two lists were created: one list with all IDUs enrolled in the harm reduction NGO clinics in the city and another with all IDUs enrolled in the methadone maintenance clinics in the city. Using the two lists, the Department of Public Health is able to compare the clients of each type of clinic and estimate the number of IDUs in Al Rabia.

The results of the two lists are provided below.

Number of IDUs in Al Rabia, Globa, 2008

Methadone clinic list	Harm-reduction NGO clinic list		Total
	Present	Absent	
Present	296	441	737
Absent	350	x	
Total	646		N

How would you estimate the number of IDUs in Al Rabia, Globa?

Capture-recapture
Exercise solution:

If 646 IDUs are present on the methadone clinic registration list and 737 IDUs are present on the harm reduction NGO clinic list and 296 are present on both lists and N = MC/R

Then the total number of IDUs = 646 x 737/296 = 1608.

Acknowledgements

The material provided in this annex was adapted from the UNAIDS/WHO report *Estimating the size of populations at risk for HIV* prepared by Elizabeth Pisani.

UNAIDS/WHO Working Group on HIV/AIDS/STI Surveillance. Estimating the size of populations at risk for HIV. Issues and methods update. July 2003. WHO/UNAIDS. Geneva, Switzerland.

The UNAIDS/WHO Working Group on Global HIV/AIDS/STI Surveillance, Guidelines on Estimating the Size of Populations Most at Risk to HIV have recently been updated and should be available to the public in 2010.

NOTES

Annex 1.3. Choosing an HIV Test

This annex describes different options for HIV testing and provides the rationale for each.

Through reading this annex you will be able to:

- describe the advantages and disadvantages of different HIV testing options
- describe how to choose a strategy for HIV testing
- understand the difference between *sensitivity* and *specificity* of a laboratory test
- identify the phases of the testing process and what quality control and quality assurance programmes should be implemented in each phase.

Selecting an HIV Antibody Test

There has been much development in HIV diagnostic technology since the first HIV antibody tests became commercially available in 1985. Currently, a wide range of different HIV antibody tests is available. Most are enzyme immunoassays (EIAs, formerly known as *ELISA*) tests and can be performed either as conventional tests in the laboratory or as rapid tests.

Conventional EIAs

For many years, HIV testing was done using two different types of antibody tests to determine if someone was infected with HIV. The testing algorithm consisted of two separate tests done on the same small sample of blood:

- an initial EIA
- if the EIA was positive, a confirmatory test (a Western blot assay or indirect immunofluorescense assay, which use different technologies to measure the presence of antibodies to HIV).

Conventional EIAs are quantitative tests. This means they measure the concentration of HIV antibodies in a specimen. Some EIAs can measure antibodies to both *HIV-1* and *HIV-2*, which is important in countries where both strains are present. These tests usually require a properly trained laboratory technician and specific laboratory equipment.

They use chemicals that combine with HIV antibodies and cause colour changes, as follows (next page):

Conventional EIAs, continued

- The more HIV antibody that is present, the darker the colour will be.
- The colour change is read by a machine that reports the intensity of the colour as *optical density*.
- Test kit manufacturers establish a certain optical density above which specimens are positive and below which specimens are negative.
- Depending on the testing strategy used, either a single positive specimen or a series of positive specimens will be reported as positive to the surveillance system or clinician.

Rapid tests

Rapid tests are a type of EIA that produces results in 10 to 30 minutes. They are simpler to use than conventional EIAs and can be done either in laboratories or in the field. They are qualitative tests that also use EIA methods to determine if a specimen is positive or negative. Unlike for conventional EIAs, no optical density readings are reported for rapid tests. Instead, there is a predetermined optical density built into the test kit above which a colour change will occur, indicating a positive result. In countries with limited laboratory infrastructure, the use of HIV rapid testing algorithms has been more possible and is as effective as conventional EIAs done in laboratories.

Advantages of rapid test

The major advantage of rapid tests is that results are available quickly—usually within 10 to 30 minutes. They also are simpler to perform. Rapid tests require less laboratory equipment and fewer skilled staff than conventional EIAs. Rapid test kits do not need to be refrigerated. Also, they can be used for testing small quantities of blood, such as from finger-sticks.

The characteristics of EIAs and HIV rapid tests are compared in Table 1 on the next page.

Advantages of rapid test, continued

Table 1. Comparing EIAs and HIV rapid tests

	EIAs	Rapid Tests
Time to result	>60 minutes	10-30 minutes
Testing volume	Suitable for large volume and batch testing	Suitable for small and large volumes
Staff requirements	Skilled technical staff required	Less skill required
Equipment requirements	Requires complex equipment, maintenance	None to minimal equipment
Storage	Test kits require refrigeration	Most test kits stored at room temperature

Source: CDC. adapted from *Module 3: Overview of HIV Testing Technologies.* Centers for Disease Control and Prevention. Atlanta. 2005

Discussing the table

Looking at Table 1, answer the following questions:

a. Which test requires less laboratory equipment and is easier to perform?

b. Where refrigeration is not available, which test would be more appropriate?

Oral fluid and urine tests

More recently developed EIAs look for antibodies in oral fluid or urine. In general, oral tests are more sensitive than urine tests, and urine tests are rarely used. Oral tests are not suitable for unlinked anonymous testing (UAT) because they cannot be performed on specimens that are stored or left over from other testing.

Whichever test is chosen, it is essential that the results given to people be reliable. Additionally, in HIV surveillance, it is important to consider the step-by-step procedure, the laboratory-testing *algorithm*, which will most accurately detect HIV infections in a population.

Selecting an HIV Testing Algorithm

A testing algorithm describes the combination and sequence of specific HIV tests (assays) used within an HIV testing strategy.

Reliability and accuracy of tests

Different algorithms have certain limitations on how well they can detect all persons who have a disease and also how well they can detect all persons who do not have a disease. These limitations are described below, and are shown in Table 2:

- Test results are *true positives* if they are positive and a patient truly has the disease.
- Test results are *false positives* if they are positive and a person does not have the disease.
- Results are *true negatives* if they are negative and a person does not have the disease.
- Results are *false negatives* if they are negative and a person truly has the disease.

Table 2. True positives, false positives, true negatives, false negatives.

	Patient has the disease	**Patient does not have the disease**
Positive test result	True positive	False positive
Negative test result	False negative	True negative

Discussing the table

Looking at Table 2, answer the following questions:

a. If a patient has a disease, but the test result for the disease is negative, what is this result known as?

b. Can you think of some problems that might be associated with a false negative? A false positive?

Sensitivity and specificity

Sensitivity and specificity are terms used to quantify how well a test performs.

- Sensitivity refers to the ability of a test to detect all persons with a disease. It is the proportion of people whose test results are positive, divided by all persons who truly have the disease.
- Specificity refers to a test's ability to detect all persons who do not have a disease. It is the proportion of persons whose test results are negative, divided by all persons who truly do not have the disease.

Positive and negative predictive values

There are two other ways to convey how well a test performs. These are *positive predictive value* (sometimes called predictive value positive) and *negative predictive value* (sometimes called predictive value negative). They are expressed in terms of what proportion of positive or negative test results identify people who truly have or do not have a disease.

In general, the more frequent a disease is in a population, the higher the positive predictive value of a test will be. Thus, the positive predictive value of an HIV test will be higher in higher prevalence areas. It will also be higher in populations more likely to be infected, such as patients with AIDS.

Table 3. A guide for calculating sensitivity and specificity.

Test result	Disease		Total
	Present	Absent	
Positive	a	b	a + b
Negative	c	d	c + d
Total	a + c	b + d	a + b + c + d

In Table 3:

- Sensitivity is a/(a+c)
- Specificity is d/(b+d)
- Positive predictive value is a/(a+b)
- Negative predictive value is d/(c+d).

An ideal test will have high sensitivity, specificity, positive predictive value, and negative predictive value.

How HIV prevalence affects test selection

The determinants of predictive values are the specificity and sensitivity of the test and the prevalence of HIV in the population. Even with a test that has high sensitivity and high specificity, and is therefore accurate, the positive predictive value may not be high enough in settings with low HIV prevalence.

In general, the higher the prevalence of HIV infection in the population, the more likely that a person with a positive test result is truly infected. The probability that a person with a negative test result is uninfected declines slightly as HIV prevalence increases. It is necessary to conduct a second or supplemental test if the first test is reactive, as this greatly increases the positive predictive value.

In settings with a *low-level epidemic*, tests with a sensitivity or specificity greater than 99% should be used to achieve satisfactory positive predictive values.

Studies have shown that the sensitivity and specificity of rapid tests are similar to those of conventional EIAs.

Selection of HIV Testing Algorithms for Surveillance

Selecting an HIV testing strategy

The selection of the HIV antibody tests and testing algorithms is a responsibility of national governments and is generally performed by health ministries and national AIDS control programmes.

UNAIDS and WHO recommend three criteria for choosing an HIV testing algorithm or strategy, which is selecting the appropriate HIV testing technologies and combination of tests:

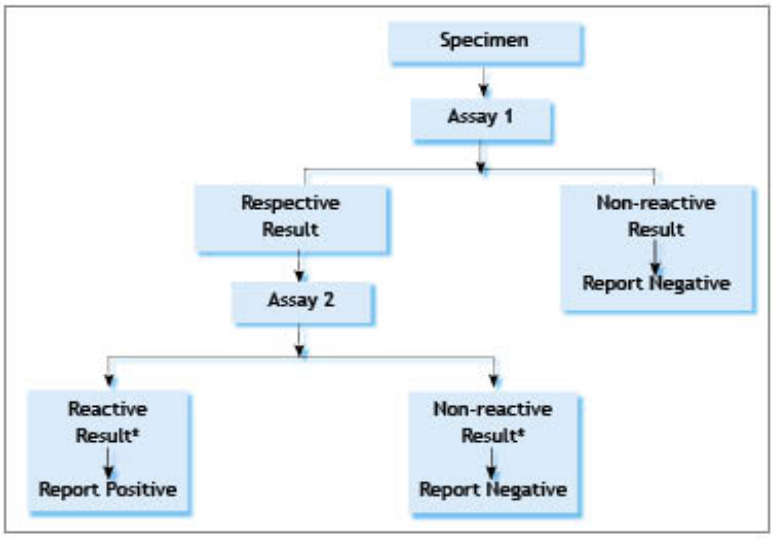
1. goal of the test, such as surveillance, blood screening, or diagnosis
2. sensitivity and specificity of the test(s) being used
3. the positive predictive value of the testing algorithm, which is linked to the prevalence of HIV infection in the population.

After these three criteria are defined, an HIV testing strategy can be selected to maximise sensitivity and specificity while minimising cost.

Recently, the WHO/UNAIDS HIV surveillance working group recommended that the testing strategy of serial testing with two tests be used regardless of HIV prevalence for surveillance (Figure 1). This concept replaces the previous options of strategies according to prevalence. The strategy states:

- A two-test strategy is recommended regardless of HIV prevalence.
- Rapid tests, automated EIAs and combinations are appropriate for the two-test strategy.
- The Western blot assay is not recommended for surveillance testing.
- Test 1 should be more sensitive and test 2 should be more specific.

Figure 1. Strategy for HIV testing for surveillance.



Testing strategy when returning results

If you are testing for diagnosis and test results will be returned, be sure to use a diagnostic HIV testing algorithm appropriate for the prevalence in your country.

In settings where the prevalence is presumed to be equal to or greater than 5% in the sample population, the WHO recommends further testing on specimens with discordant results, meaning specimens that are reactive to the first assay but non-reactive to the second assay. Using this algorithm:

- If the third test is non-reactive the result should be considered negative and the individual should be reported as HIV-negative.

Testing strategy when returning results, continued

- If the third test is reactive, the result should be considered HIV antibody indeterminate and further testing is recommended on a second specimen that will be taken after 14 days.

In settings where the prevalence is presumed to be less than 5% in the sample population, the WHO recommends performing a third assay on specimens that are reactive to both the first and second assays. A third assay should be used to confirm the initially HIV reactive specimens because the positive predictive value based on the two initial results will be too low given the low HIV prevalence in the population. In this algorithm:

- If the third test is also reactive, the results can be reported as HIV-positive.
- If the third test is non-reactive, the results should be considered HIV indeterminate and further testing should be done in 14 days.

Testing for HIV-1 versus HIV-2

We can assume that HIV-2 (one of the sub-types of HIV that is primarily located in West Africa) can be found in all sub-Saharan African countries. Therefore, the HIV test performed must be able to detect the presence of both HIV-1 and HIV-2. Most rapid tests and EIAs detect both HIV-1 and HIV-2 but do not differentiate between them.

It is sometimes important for surveillance efforts to differentiate between HIV-1 and HIV-2 infections to determine how the infection is spreading in the country. If a country has a new introduction of HIV-2 from a neighbouring country, for instance, surveillance officers can follow its distribution in the population over the next few years. A laboratory test is available that differentiates between HIV-1 and HIV-2. This test should be performed in referral laboratories.

Ensuring Quality in the Laboratory

To ensure the reliability of test results, a laboratory needs to have quality control and quality assurance systems in place and to follow procedures carefully.

Quality control

Quality control (QC) assesses a laboratory's machinery to check that the HIV test results obtained from a specimen are correct. For QC of the laboratory equipment, positive and negative controls must be run on the machines from time to time to verify that they detect HIV antibodies accurately. The manufacturer of the test kit or a reference laboratory can provide these controls.

- *Positive controls* are specimens known to be positive.
- *Negative controls* are specimens known to be negative.

By running these specimens, laboratories can test their procedures and reagents to see if there are any problems. They should get the correct results 100% of the time.

Quality assurance

Quality assurance (QA) assesses a laboratory's processes for obtaining tests results comparing the results for a specific specimen with other tests conducted on the same specimen. This can be done by one of the following, described in more detail later in this unit:

- the laboratory itself (internal QA)
- an outside reference laboratory (external QA).

To conduct QA of the entire HIV testing process, laboratories should routinely be monitored during the pre-analytical, analytical, and post-analytical phases of the testing process.

- The pre-analytical phase includes activities that occur before a specimen is actually tested.
- The analytical phase occurs during the actual testing of the specimen.
- The post-analytical phase refers to activities done after a specimen has been tested.

QA and the phases of the testing process

There are a variety of components in each phase of the testing process that should be monitored by QA programmes. These components are listed in Table 4, on the next page.

QA and the phases of the testing process, continued

Table 4. Components for review by QA programmes in the pre-analytical, analytical, and post-analytical phases of the testing process.

Pre-Analytical Phase	Analytical Phase	Post-Analytical Phase
▪ training ▪ laboratory safety ▪ number of trained personnel available and capable of performing HIV testing ▪ specimen collection, labelling, and transport conditions ▪ deciding on handling of specimens before testing ▪ deciding on the sources and types of specimens to be tested ▪ deciding on the number of specimens tested ▪ selecting test kits ▪ expiration dates of test kits. Kits need to be used before expiration dates. Older kits should be used before newer kits. ▪ HIV test kit reagents. Reagents must be stored at the appropriate temperature as specified by the manufacturer. Certain reagents (such as conjugates for EIAs) may require refrigeration	▪ processing and storing specimens ▪ written procedure manual ▪ reagent preparation ▪ testing performance ▪ performance and maintenance of equipment (such as spectrophotometers and washers) ▪ correct use of reagents ▪ including internal QCs in the test kits ▪ QC monitoring procedure	▪ interpreting results ▪ transcribing results, such as recording results on the correct identifier code ▪ entering data into the tracking system (computer or hard copy) ▪ maintaining records ▪ reviewing QCs

QA and the phases of the testing process, continued

Discussing the table

Looking at Table 4, answer the following questions:

a. In which phase are results analysed and interpreted?

b. In which phase are specimens tested?

Internal QA

Internal QA is meant to allow laboratory technicians to check their performance for themselves. Below is an example of a procedure for internally testing quality, although it may not be appropriate for all sites:

- Set aside an *aliquot* of every twentieth negative and every fifth positive specimen and mark it with an identification number. The specimens are stored in a "deep" or non–frost-free freezer (-70°C).
- Once there are sufficient stored aliquots, the stored specimens are tested a second time.
- The laboratory technicians then compare the initial results and the results of re-testing, to monitor the reliability of their techniques.

External QA

Countries should require that all laboratories at all levels, including the national reference laboratory, HIV laboratories in hospitals, blood transfusion services, and private HIV laboratories, participate in an external QA programme to monitor and evaluate each facility's performance.

External QA programmes may be instituted by a national or international *reference laboratory* which functions as a recognised centre of expertise and standardisation of diagnostic techniques. The steps to implementing an external QA programme, such as a proficiency testing programme, are listed on the following page. Proficiency testing should be done once or twice each year.

External QA, continued

1. The national reference laboratory sends all participating laboratories a proficiency panel of approximately six specimens to identify as HIV-positive or HIV-negative. Proficiency panels are a set of samples for which the test results are known by the reference laboratory. This panel should contain HIV-negative and HIV-positive samples of both weak and strong specimens. Samples should be representative of the HIV strains circulating in a country, and they should be from different stages of the disease (for instance, from early HIV infection to late-stage AIDS).

2. The panels are tested at the local laboratories in much the same way as they routinely test their specimens for HIV.

3. The local laboratories report their findings to the reference laboratory.

4. The reference laboratory collates the results and provides feedback to each participating laboratory.

External QA must be carried out for the national reference laboratory as well. This should be provided by an independent laboratory, such as the laboratory at a large university, or by one of the WHO regional QA programmes.

QA with limited laboratory infrastructure

In geographic areas with limited laboratory infrastructure, laboratories can prepare a dried blood spot on filter paper and send it to the national reference laboratory to be tested for QA purposes.

Summary

HIV antibody tests can be performed using conventional EIAs in a laboratory or using rapid tests. You should take into consideration several factors when selecting a test for your region, including the epidemic state and the available resources. To ensure the accuracy and reliability of testing equipment, QC and QA programmes should be in place for each of the main testing phases.

Annex 1.4. Required Elements of Informed Consent

The United States Code of Federal Regulations for the Protection of Human Subjects, Section §46.116, describes eight elements required in each consent process/document. Element number six is only required if the research is determined to be greater than minimal risk.

Element	**45 CFR 46.116(a)**
1.	A. a statement that the study involves research B. an explanation of the purposes of the research C. the expected duration of the subject's participation D. a description of the procedures to be followed E. identification of any procedures which are experimental
2.	a description of any reasonably foreseeable risks or discomforts to the subject
3.	a description of any benefits to the subject or to others which may reasonably be expected from the research
4.	a disclosure of appropriate alternative procedures or courses of treatment, if any, that might be advantageous to the subject
5.	a statement describing the extent, if any, to which confidentiality of records identifying the subject will be maintained
6.	A. an explanation as to whether any compensation is available if injury occurs B. an explanation as to whether any medical treatments are available if injury occurs, and, if so C. what they consist of or where further information may be obtained
7.	A. an explanation of whom to contact for answers to pertinent questions about the research B. an explanation of whom to contact for answers to pertinent questions about the research subjects' rights C. whom to contact in the event of a research-related injury to the subject
8.	A. a statement that participation is voluntary B. refusal to participate will involve no penalty or loss of benefits to which the subject is otherwise entitled C. the subject may discontinue participation at any time without penalty or loss of benefits to which the subject is otherwise entitled

Annex 1.5. Examples of Written and Verbal Informed Consent to Participate in a Survey

1.5a Sample Written Consent Form

English Version; Grade Reading Level by Flesch-Kincaid Method: 7.6

Participant Information and Informed Consent Form

The **[Agency Name]** and the Centers for Disease Control and Prevention (CDC) invite you to be part of a survey of persons who may be at risk for HIV infection. The information I will give you can help you make a good choice about joining the survey. This document is a consent form. If you decide to participate in the survey, you will be asked to sign this form. You will be given a copy to keep. Please take your time to review it. This form can be read to you or you may read it yourself. You are free to ask questions at any time. Please ask the survey staff to explain any words or information that is not clear to you.

A. Why we are doing this project

The purpose of this survey is to learn about risk for HIV. We will use this information to plan better HIV prevention and treatment programs for people in your community. Being in this survey is voluntary.

B. What will happen

If you agree to be in this survey, this is what will happen.

1. You will do a survey with a trained staff member. The survey has questions about your health, drug use, sex practices, and HIV prevention services. It will take about 40 minutes. The interview is completely confidential. We will not ask for your name or other identifying information. The survey has questions that are personal. They may be hard to talk about. You may refuse to answer any questions at any time for any reason. If you refuse to answer a question or want to end the interview you will not be punished in any way.

2. If you agree to the survey, we will offer you a free HIV test. If you already know that you are HIV-infected, we would still like to offer you an HIV test today so that we can link today's HIV test result with your survey results. If you agree to the HIV test, you will have a 10- to 15-minute HIV prevention counseling session with a trained staff member. The session will cover the meaning of results from the HIV test. You will also learn about how to reduce your chances of being infected with HIV and other infectious diseases. The HIV test will be done by a standard or rapid test as discussed below.

Standard Test

For the standard test, we will [draw less than 1 tablespoon of your blood using a needle *or* swab the inside of your mouth for oral fluid] and test it for HIV. Your test results will be ready within one week. We will set up a day and time for you to get your results. You will get counseling about what the test results mean and referrals to services, if needed. *[For sites that allow HIV test phone results:* If you cannot return for your HIV test results, you can arrange to receive your counseling and test results by telephone.]

Rapid Test
With the rapid test, you can get the result of your HIV test within 1 hour. We will [stick the tip of one of your fingers to obtain a few drops of blood *or* take a swab from your mouth]. You will get counseling about what the test result means. You will get referrals to services, if needed. If the rapid test result is reactive, or if you know you are already HIV- infected, we will [draw less than 1 tablespoon of your blood by needle *or* stick the tip of one of your fingers to obtain a few drops of blood *or* swab the inside of your mouth for oral fluid] for a second test to confirm your rapid test result. The result of the confirmatory test will be ready within one week. We will set up a day and time for you to get your results.

Linkage
We will link your test results with your survey so we can learn about sexual and drug-use risk behaviors known to be connected with HIV infection. We will link your test results using the same ID assigned to the survey. Your name will not be on the test results or the survey. No one besides you will be told your test results, and neither the survey nor the test will be placed in any medical record.

3. *[For sites doing HIV tests via blood draw only]* If you agree to an HIV test, you will also be asked to have your blood sample stored for later testing. We would like to store any blood that is left over after we do your test. We plan to use this sample for studies we will do in the future. We will store your sample with some data about you, such as your age, race, and sex. We will not put your name on the sample and there will be no way to know it is yours: thus, we will not be able to report back any test results to you. We will not test for any genetic disease or use blood for cloning or commercial purposes. You can decline to let us store your blood and still be in this survey. Your blood sample will be destroyed after this testing is completed.

4. [*For sites doing additional lab tests]* If you agree to the HIV test, we will also offer you free…

[Include any additional test to be offered, with description of procedures and samples to be obtained].

C. Things to consider
There are minimal risks from being in this survey:

1. Some of the questions in the survey are about sex and drugs and may make you feel uncomfortable. All answers you give will be kept private.

2. [*If using standard test:* Drawing blood may cause temporary discomfort from the needle stick, bruising, bleeding, light-headedness, and local infection.]

3. You may feel uncomfortable finding out you might have been infected with HIV. You can talk about your concerns with the trained staff member who tells you your HIV test results, if you wish.

4. If your HIV test result is negative, there is a slight chance that the results are wrong and that you could still be infected or test positive at some time in the future.

D. Benefits
Benefits you may get from being in this survey include:

1. You will receive some condoms and information on HIV/AIDS and STIs.

2. You will, if you wish, receive free referrals to other local programs, medical programs, support groups, and health projects, as needed.

3. If your HIV test results *[or additional tests offered]* are positive, you will be counseled about ways to prevent the spread of infection. You will also be referred for medical care.

4. If your test results are negative, you will receive counseling on how to prevent future infections.

Also, information gained from this survey will help the **[Agency Name]** to know more about HIV and how it is spread. This information will be used to improve health programs and to develop new ways of helping others prevent disease and promote good health.

E. Alternatives
If you choose not to take part in the survey but would like to take an HIV test, we will inform you of agencies or organizations that provide testing.

F. Compensation
You will be paid for the time you spend taking part in the survey. For completion of any part of the survey, you will get *[specify amount]*.

G. Persons to Contact
This survey is run by: [*name of principal investigator and phone number*]. You may call [him/her] with any questions about being in the survey.

If you have questions about your rights as a participant or if you feel that you have been harmed, contact [*IRB committee or contact name and phone number*].

If you want one, you will get a copy of this form to keep.

H. Confidentiality Statement
What you tell us is confidential. The survey staff will do everything possible to keep your participation in this survey private. Your name will be known by only a few of the survey staff. Your responses and blood samples will be labeled with a survey number only. No one except the survey staff at **[Agency Name]** and CDC will have access to the survey, except as otherwise required by law. Your responses will be grouped with survey answers from other persons.

Survey forms and handheld computers will be locked in a file cabinet at the survey office. Computers with survey data will be physically secured and protected by coded passwords. Only specific survey staff will have access to the locked file cabinet or the computers.

If you know me, you may ask for another staff member so that your answers will be fully private.

I. Costs
You will not be charged for counseling, the HIV test *[any additional tests offered]*, safer sex and HIV prevention materials, referrals to appropriate agencies, or any other services provided by this survey.

J. Right to Refuse or Withdraw

This survey is completely VOLUNTARY. You are not giving up any legal claims or rights for being a part of this survey. If you agree to participate, you are free to quit at any time. You can choose to only do the survey and not to have an HIV test. You can also choose not to recruit others.

K. Agreement
Do you have any questions?

Interviewer: Answer the participant's questions before proceeding to the next question.

You have read or had read to you the explanation of this survey, you have been given a copy of this form, the opportunity to discuss any questions that you might have and the right to refuse participation. You will now be asked to give your written consent to participate in this survey. You may choose whether or not to participate in any of the survey procedures below.

Do you agree to take part in the survey?

☐ Taking part in the survey

Do you agree to HIV counseling and testing?

☐ HIV counseling and testing

Do you agree to having other lab tests (if offered)?

☐ Having other lab tests (if offered)

Do you agree to storing a blood sample for future testing (if offered)?

☐ Storing a blood sample for future testing

If you agree to participate, you should sign below.

_____ _____
Date Signature of Survey Participant

_____ _____
Date Signature of Person Obtaining Consent

(If no to taking part in the survey, the interviewer checks the box for this item:)

☐ Decline participation

If declined:

We're interested in knowing why people do not want to do this survey**. Would you mind telling me which of the following best describes the reason you do not want to do this** survey**?**

You don't have time……..1
You don't want to talk about these topics…… 2
Some other reason, or ……..…….....3
You'd rather not say why…….....9

Annex 1.5. Examples of Written and Verbal Informed Consent to Participate in a Survey - continued

1.5b Sample Verbal Consent Form (not requiring written signature)

English Version; Grade Reading Level by Flesch-Kincaid Method: 7.6

Information Sheet for Survey Participants

The **[Agency Name]** and the Centers for Disease Control and Prevention (CDC) invite you to be part of a survey of persons who may be at risk for HIV infection. The information I will give you can help you make a good choice about joining the survey. This document gives you information about the survey. You will be given a copy to keep. Please take your time to review it. This form can be read to you or you may read it yourself. You are free to ask questions at any time. Please ask the survey staff to explain any words or information that is not clear to you.

A. Why we are doing this project

The purpose of this survey is to learn about risk for HIV. We will use this information to plan better HIV prevention and treatment programs for people in your community. Being in this survey is voluntary.

B. What will happen

If you agree to be in this survey, this is what will happen.

1. You will do a survey with a trained staff member. The survey has questions about your health, drug use, sex practices, and HIV prevention services. It will take about 40 minutes. This is an anonymous survey. We will not ask for your name or other identifying information. The survey has questions that are personal. They may be hard to talk about. You may refuse to answer any questions at any time for any reason. If you refuse to answer a question or want to end the interview you will not be punished in any way.

2. If you agree to the survey, we will offer you a free HIV test. If you already know that you are HIV-infected, we would still like to offer you an HIV test today so that we can link today's HIV test result with your survey results. If you agree to the HIV test, you will have a 10- to 15-minute HIV prevention counseling session with a trained staff member. The session will cover the meaning of results from the HIV test. You will also learn about how to reduce your chances of being infected with HIV and other infectious diseases. The HIV test will be done by a standard or rapid test as discussed below.

Standard Test

For the standard test, we will [draw less than 1 tablespoon of your blood using a needle *or* swab the inside of your mouth for oral fluid] and test it for HIV. Your test results will be ready within one week. We will set up a day and time for you to get your results. You will get counseling about what the test results mean and referrals to services, if needed. *[For sites that allow HIV test phone results:* If you cannot return for your HIV test results, you can arrange to receive your counseling and test results by telephone.]

Rapid Test
With the rapid test, you can get the result of your HIV test within 1 hour. We will [stick the tip of one of your fingers to obtain a few drops of blood *or* take a swab from your mouth]. You will get counseling about what the test result means. You will get referrals to services, if needed. If the rapid test result is reactive, or if you know you are already HIV- infected, we will [draw less than 1 tablespoon of your blood by needle *or* stick the tip of one of your fingers to obtain a few drops of blood *or* swab the inside of your mouth for oral fluid] for a second test to confirm your rapid test result. The result of the confirmatory test will be ready within one week. We will set up a day and time for you to get your results.

Linkage
We will link your test results with your survey so we can learn about sexual and drug-use risk behaviors known to be connected with HIV infection. We will link your test results using the same ID assigned to the survey. This is an anonymous test. Your name will not be on the test results or the survey. No one besides you will be told your test results, and neither the survey nor the test will be placed in any medical record.

3. *[For sites doing HIV tests via blood draw only]* If you agree to an HIV test, you will also be asked to have your blood sample stored for later testing. We would like to store any blood that is left over after we do your test. We plan to use this sample for studies we will do in the future. We will store your sample with some data about you, such as your age, race, and sex. We will not put your name on the sample and there will be no way to know it is yours: thus, we will not be able to report back any test results to you. We will not test for any genetic disease or use blood for cloning or commercial purposes. You can decline to let us store your blood and still be in this survey. Your blood sample will be destroyed after this testing is completed.

4. [*For sites doing additional lab tests]* If you agree to the HIV test, we will also offer you free

[Include any additional test to be offered, with description of procedures and samples to be obtained].

C. Things to consider
There are minimal risks from being in this survey:

1. Some of the questions in the survey are about sex and drugs and may make you feel uncomfortable. All answers you give will be kept private.

2. [*If using standard test:* Drawing blood may cause temporary discomfort from the needle stick, bruising, bleeding, light-headedness, and local infection.]

3. You may feel uncomfortable finding out you might have been infected with HIV. You can talk about your concerns with the trained staff member who tells you your HIV test results, if you wish.

4. If your HIV test result is negative, there is a slight chance that the results are wrong and that you could still be infected or test positive at some time in the future.

D. Benefits
Benefits you may get from being in this survey include:

1. You will receive some condoms and information on HIV/AIDS and STIs.

2. You will, if you wish, receive free referrals to other local programs, medical programs, support groups, and health projects, as needed.

3. If your HIV test results *[or additional tests offered]* are positive, you will be counseled about ways to prevent the spread of infection. You will also be referred for medical care.

4. If your test results are negative, you will receive counseling on how to prevent future infections.

Also, information gained from this survey will help the **[Agency Name]** to know more about HIV and how it is spread. This information will be used to improve health programs and to develop new ways of helping others prevent disease and promote good health.

E. Alternatives
If you choose not to take part in the survey but would like to take an HIV test, we will inform you of agencies or organizations that provide testing. You will get no medical treatment in this survey.

F. Compensation
You will be paid for the time you spend taking part in the survey. For completion of any part of the survey, you will get *[specify amount]*.

G. Persons to Contact
This survey is run by: [*name of principal investigator and phone number*]. You may call [him/her] with any questions about being in the survey.

If you have questions about your rights as a participant or if you feel that you have been harmed, contact [*IRB committee or contact name and phone number*].

If you want one, you will get a copy of this form to keep.

H. Confidentiality Statement
What you tell us is confidential. Your responses and blood samples will be labeled with a survey number only. No one except the survey staff at **[Agency Name]** and CDC will have access to the survey, except as otherwise required by law. Your responses will be grouped with survey answers from other persons.

Survey forms and handheld computers will be locked in a file cabinet at the survey office. Computers with survey data will be physically secured and protected by coded passwords. Only specific survey staff will have access to the locked file cabinet or the computers.

If you know me, you may ask for another staff member so that your answers will be fully private.

I. Costs
You will not be charged for counseling, the HIV test *[any additional tests offered]*, safer sex and HIV prevention materials, referrals to appropriate agencies, or any other services provided by this survey.

J. Right to Refuse or Withdraw
This survey is completely VOLUNTARY. You are not giving up any legal claims or rights for being a part of this survey. If you agree to participate, you are free to quit at any time. You can choose to only do the survey and not to have an HIV test. You can also choose not to recruit others.

K. Agreement
Do you have any questions?

Interviewer: Answer the participant's questions before proceeding to the next question.

You have read or had read to you the explanation of this survey, you have been given a copy of this form, the opportunity to discuss any questions that you might have and the right to refuse participation. I am going to ask for your consent to participate in this survey. You may choose whether or not to participate in any of the survey procedures below.

Interviewer: Ask and document the participant's response to each question below:

Do you agree to take part in the survey?
☐ Taking part in the survey

Do you agree to HIV counseling and testing?
☐ HIV counseling and testing

Do you agree to having other lab tests (if offered)?
☐ Having other lab tests (if offered)

Do you agree to storing a blood sample for future testing (if offered)?
☐ Storing a blood sample for future testing

(If no to taking part in the survey, the interviewer checks the box for this item:)
☐ Declined participation

If declined:
We're interested in knowing why people do not want to do this survey**. Would you mind telling me which of the following best describes the reason you do not want to do this** survey**?**

You don't have time……..1
You don't want to talk about these topics…… 2
Some other reason, or ……..3
You'd rather not say why…….....9

_____ _____
Date Signature of Person Conducting Informed Consent Process

Unit 2

Sex Workers

Overview

What this unit is about

This unit describes the background and special considerations for conducting behavioural surveillance and HIV sero-surveillance among sex workers (SWs). The unit ends with an extensive case study concerning SWs and specific study issues.

Warm-up questions

1. True or false? SWs can contribute disproportionately to the sexual transmission of HIV because of their large number of sexual partners.

   True False

2. Other than brothels, what are some of the locations where direct SWs (SWs who work exclusively in sex work and have no other occupation) can be found?

   a.
   b.

3. What term is used to describe SWs who do not engage in sex work full time and may have another source of income? (They are also called casual SWs or clandestine SWs.)

4. True or false? Surveillance co-ordinators should meet with SWs to use their expertise in designing the approach and questionnaires for behavioural surveillance.

   True False

5. SWs and their clients are often a _____to other high-risk populations. Clients of SWs, for example, may transmit HIV to their wives and non-commercial sex partners.

6. Name a sampling method that could be used among highly mobile SWs, such as those who do not work in brothels.

Introduction

What you will learn

By the end of this unit, you should be able to:

- understand the diversity of sex work
- understand the role of sex workers in the HIV epidemic
- describe options for sampling sex workers
- describe the special ethical considerations associated with conducting HIV surveillance activities among sex workers.

Background

This unit focuses on the special issues in conducting *behavioural surveillance* and HIV *sero-surveillance* in *sex workers* (SWs).

Sex work, or the exchange of sex for money, is extremely widespread and occurs in every region of the world. Sex work includes many practises and occurs in a wide range of settings. Two broad categories are often used to describe sex work: "*direct sex work*" and "*indirect sex work.*" The typical features of these categories are shown in Table 2.1.

Table 2.1. Comparing direct and indirect SWs.

Direct sex workers	Indirect sex workers
▪ have little or no source of income outside of sex work ▪ are also called formal SWs ▪ can be found in brothels ▪ can be found in high concentrations in streets, hotels, bars, massage parlours ▪ may work by special arrangement via telephone or Internet ▪ may be trafficked (that is, bought and sold) with little freedom of mobility and difficult access to persons other than their handlers or clients ▪ may be registered in areas where sex work is legal or tolerated; registries of direct SWs may be maintained through *sexually transmitted infection* (STI) clinics to monitor routine STI screening and treatment ▪ may identify themselves as SWs	▪ are those who may have another source of income or do not engage in sex work full time ▪ are also called casual SWs, clandestine SWs, or SWs ▪ may provide sex services in specific locations where they are employed, such as bars, hotels or massage parlours, that are not necessarily or exclusively associated with sex work ▪ may work by special arrangement via telephone or Internet ▪ are unlikely to be included in registries or lists of SWs routinely screened at STI clinics ▪ may not identify themselves as SWs

Discussing the table

Looking at Table 2.1, on the previous page, answer the following questions:

a. What is another name for indirect sex workers?

b. If a woman sells sex as her only occupation, as which type of worker can she be classified?

SWs may cross between direct and indirect sex work or may enter and exit sex work over time.

Some aspects of sex work may not follow these categories. Sex may be bartered for material needs, school fees, or illicit drugs, for example. This behaviour is called *transactional sex*. In some areas, persons who engage in transactional sex are not considered sex workers. In addition, women who engage in this behaviour typically do not consider themselves sex workers. Surveillance approaches described in this module are most applicable to "direct" sex work, and to some extent "indirect" sex work, and would not accurately capture transactional sex.

Throughout the world, men also buy sex from male and *transgendered* (that is, biologically male people who present as females) SWs. These populations often are severely affected by HIV. Many of the methods used in conducting surveillance in *male sex workers* (MSWs) are similar to those used with *female sex workers* (FSWs). In other ways, however, surveillance among MSWs is very different from surveillance among FSWs. As an example, the *formative assessment* phases should identify issues with accessing *men who have sex with men* (MSM) and tracking behaviours specific to male-male sexual practises. Surveillance measures and approaches to sampling MSWs also are discussed in the unit related to MSM. You should keep in mind that not all MSWs are MSM; in some settings MSWs may identify as heterosexual and have female clients.

Role of SWs in the HIV epidemic

SWs are at high risk both for getting HIV and STIs from their clients and for transmitting them to their clients and their non-paying sex partners. Factors that may increase HIV risk among SWs include:

- large number of daily clients, increasing the probability of exposure to HIV and STIs
- high levels of *partner concurrency* (that is, having extensive sexual network connections to many persons at the same time, which increases the spread of HIV and STIs)
- high frequency use of commercial sex by men in the population
- high levels of other STIs that enhance HIV transmission
- high levels of injecting drugs
- high frequency of sex under the influence of alcohol or drugs, which often affects the ability to negotiate condom use
- large number of clients under the influence of alcohol or drugs
- loss of control over condom use due to financial and physical coercion or violence
- having non-client sex partners, both steady and non-steady, with whom condoms are not used
- high levels of mobility and travel; for example, to areas that have higher or lower HIV prevalence
- difficult access to HIV and STI prevention programmes due to the illegal and stigmatised nature of sex work.

Prevalence of HIV among SWs

The *prevalence* of HIV among SWs varies by country and region, as illustrated in the following data:

- In Mali, over one in three (35%) FSWs participating in a 2006 survey tested HIV-positive, a higher rate than from studies in previous years. Prevalence was 50% among women selling sex for over six years and 58% among women older than 40 years (Ministere de la Sante du Mali, 2006, UNAIDS).
- In Pakistan in 2001, 1.7% of FSWs in Sindh Province were found to be infected with HIV (UNAIDS).
- Among Tunisian bar girls tested for HIV in 1989 and 1992, the prevalence of HIV was found to be 1.3% and 2.3%, respectively (UNAIDS).
- In Nepal, 16% of street-based FSWs operating in Kathmandu valley were HIV-positive in 2001; however, more recent studies have found much lower infection levels of 2% or less. MSWs in two 2005 Kathmandu studies showed an HIV prevalence of 4% and 5% (UNAIDS).
- According to the results of the HIV prevalence survey conducted among MARPs in 2007 in the Republic of Moldova, HIV prevalence among SWs was 11% (UNGASS).
- In Guyana, FSWs in 2006 were found to have an HIV prevalence of 31% (Allen et al., 2006, UNAIDS).
- At 11%, HIV prevalence among MSWs is considerably higher than the 1.8% and 2.6% prevalence found in separate 2006 studies among FSWs in Paraguay (UNAIDS, Bautista et al, 2006; National AIDS Program Paraguay, 2006c).
- Available data from 19 cities across Kazakhstan suggest that HIV prevalence in SWs was 2% at the end of 2005, among the SWs in this study almost 12% were also injecting drugs (www.euro.who.int/aids/ctryinfo/overview/20060118_24).

Role of SWs in surveillance

SWs can play an important role in HIV surveillance at all states of the epidemic:

- In countries with *low-level epidemics,* where the HIV prevalence has not consistently exceeded 5% in any defined sub-population, SWs may be the first to be detected with HIV infection.
- SWs are often one of the first populations to reach HIV prevalence levels above 5%, leading to a country's epidemic classification as *concentrated*.

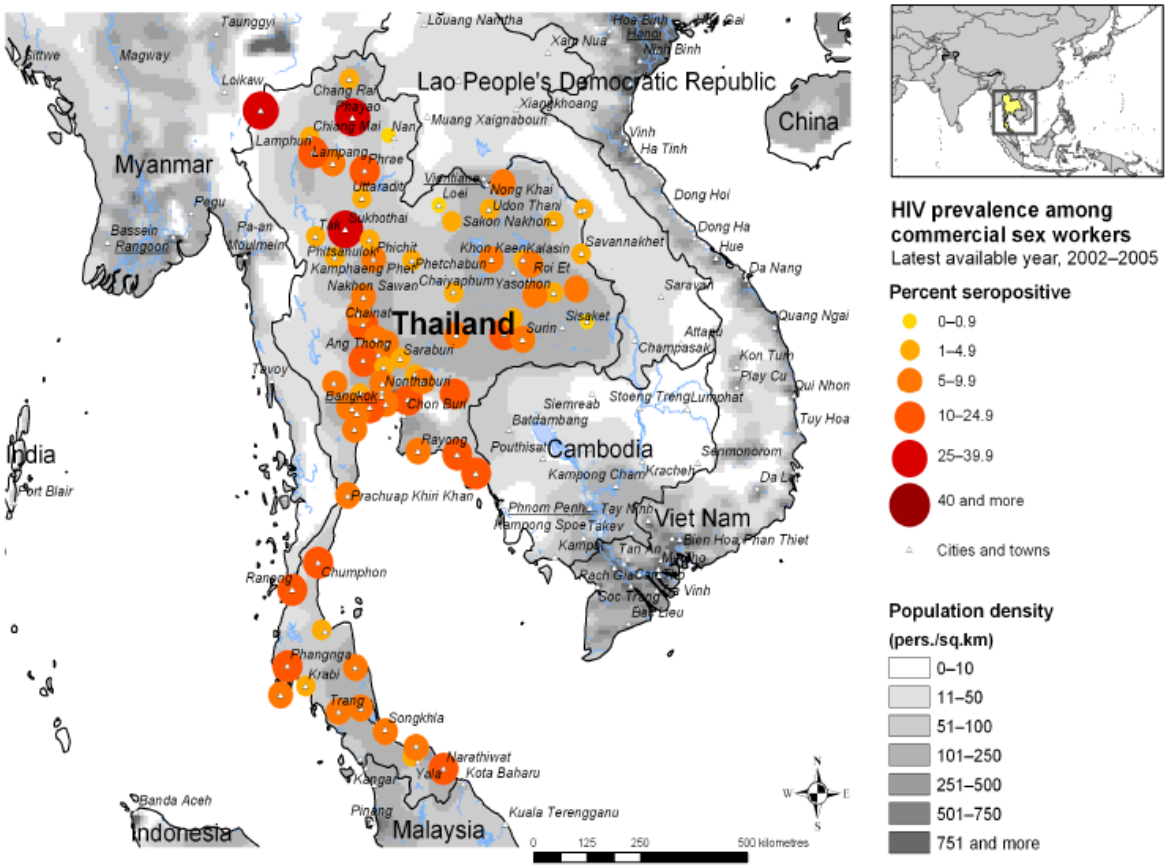
- In *generalised epidemics,* where transmission is widespread in the general population, behavioural changes in response to prevention programmes may be detected first among SWs. The results of consistent condom use, for example, may be detected first among SWs.

SWs can contribute disproportionately to the sexual transmission of HIV because of their large number of sexual partners and other factors listed above. Therefore, behavioural and HIV sero-surveillance among SWs plays a central role in determining the magnitude and direction of the HIV epidemic in all epidemic states.

Mapping the geographical distribution of HIV prevalence among SWs may help both to interpret the national coverage of the HIV surveillance system and to explain differences in levels of prevalence. Maps also can show HIV prevalence in relation to population density, major urban areas, and communication routes.

Role of SWs in surveillance, continued

Figure 2.1. HIV prevalence among commercial sex workers, Thailand, 2002-2005.



Source: WHO Epi Fact Sheet, Thailand 2006.

Discussing the figure

Looking at Figure 2.1, answer the following questions:

a. What areas in Thailand have the highest HIV prevalence among SWs?

b. What is the relation between population density and HIV prevalence among SWs?

c. What are some of the limitations of Figure 2.1?

Bridges and overlap with other populations

SWs and their clients are often *bridges* to other *high-risk populations*. Male clients of FSWs or MSWs, for example, may transmit HIV to their wives and non-commercial sex partners who are steady and non-steady.

Some groups of men become the clients of SWs more frequently than the general population. Depending on the country, these may include:

- people in occupations that require travel
- military personnel
- police officers
- STI clinic patients.

In some settings, SWs also overlap with many other high-risk populations covered in this module. SWs are found among *injecting drug users* (IDUs), street children, and prisoners.

Additionally, many SWs are mobile. Some are trafficked from rural areas or across international borders, while others voluntarily migrate to urban centres or other areas where men congregate, such as truck stops. As an example, an estimated 8000 FSWs operate along the trans-Africa highway that links Mombassa, Kenya and Kampala, Uganda (UNAIDS).

The often desperate conditions of being a refugee or involuntary migrant may force women to sell sex to survive. SWs may include migrants who later become SWs and women and children who are trafficked for the purpose of sex work.

Conducting a Formative Assessment

Consider where to find SWs

Surveillance requires gaining access to the full range of SWs sub-populations and areas. Locating and gaining access to all areas where SWs can be found can be difficult, however.

You can locate and gain access to SWs by:

- visiting the venues where they gather
- interviewing and working with the people who aid or regulate contact
- collaborating with organisations that provide services to SWs.

Because SWs are often socially marginalised and rigidly controlled or trafficked by their handlers, forming *alliances* may be necessary to obtain surveillance data. Examples of alliances for gaining access to SWs include:

- influential current and former SWs
- police
- handlers or other *gatekeepers,* such as pimps, madams, and brothel managers or owners
- governmental and non-governmental organisations conducting SW HIV prevention and care programmes
- national and international SW advocacy groups
- national and international organisations that broadly advocate for women's interests
- doctors and pharmacists who provide services to SWs
- rickshaw and taxi drivers.

Consider where to find SWs, continued

These people and organisations also can later assist with implementing surveillance activities. As an example, former SWs can be hired and trained as recruiters or interviewers.

The places where SWs congregate include:

- brothels, hotels, bars, discos, and massage parlours where sex work is known to take place
- streets, parks, tourist sites, truck stops, and other outdoor areas where people who may be looking for SWs may be found.

You can make a count or estimate of the number of SWs associated with each of these places. As examples:

- For each brothel, make a *census* for the number of SWs.
- For a particular street, count the number of SWs found during four-hour time periods at different times of the day and during different days of the week or month.
- For each bar, count the number of SWs found during four-hour time periods at different times of the day and during different days of the week or month.

With each venue and time period, the types of SWs should be recorded, if possible. How many SWs are part-time versus full-time, for example? How many are direct SWs versus indirect SWs?

Some SWs do not congregate in a particular location. They are accessed by clients through other channels, such as newspaper ads, Internet ads, the telephone, or word of mouth. Such SWs may not have agents who arrange meetings. At present, the role these types of SWs play in the HIV epidemic is thought to be small. The ways in which they can be included in future surveillance activities is under research.

In addition, formative assessment requires an assessment of how *networked*, or interconnected, SWs are with each other in venues where they work and types of sex work in which they are involved. Do brothel-based SWs interact with street-based or indirect SWs, for instance? Do FSWs interact with male or transgendered SWs?

Selecting a Sampling Method

In the past, samples of SWs and other hard-to-reach populations were *convenience* or *non-probability samples*, such as surveys of SWs attending STI clinics, or interviews of the most visible SWs found in certain areas. Although non-probability samples can provide some information, these data can be biased for a number of reasons. HIV prevalence and risk behaviours, for example, may be different in the most visible sub-populations of SWs compared with those that are more hidden. There are probability and quasi-probability sampling methods now available that can successfully be used to obtain more representative samples of SWs.

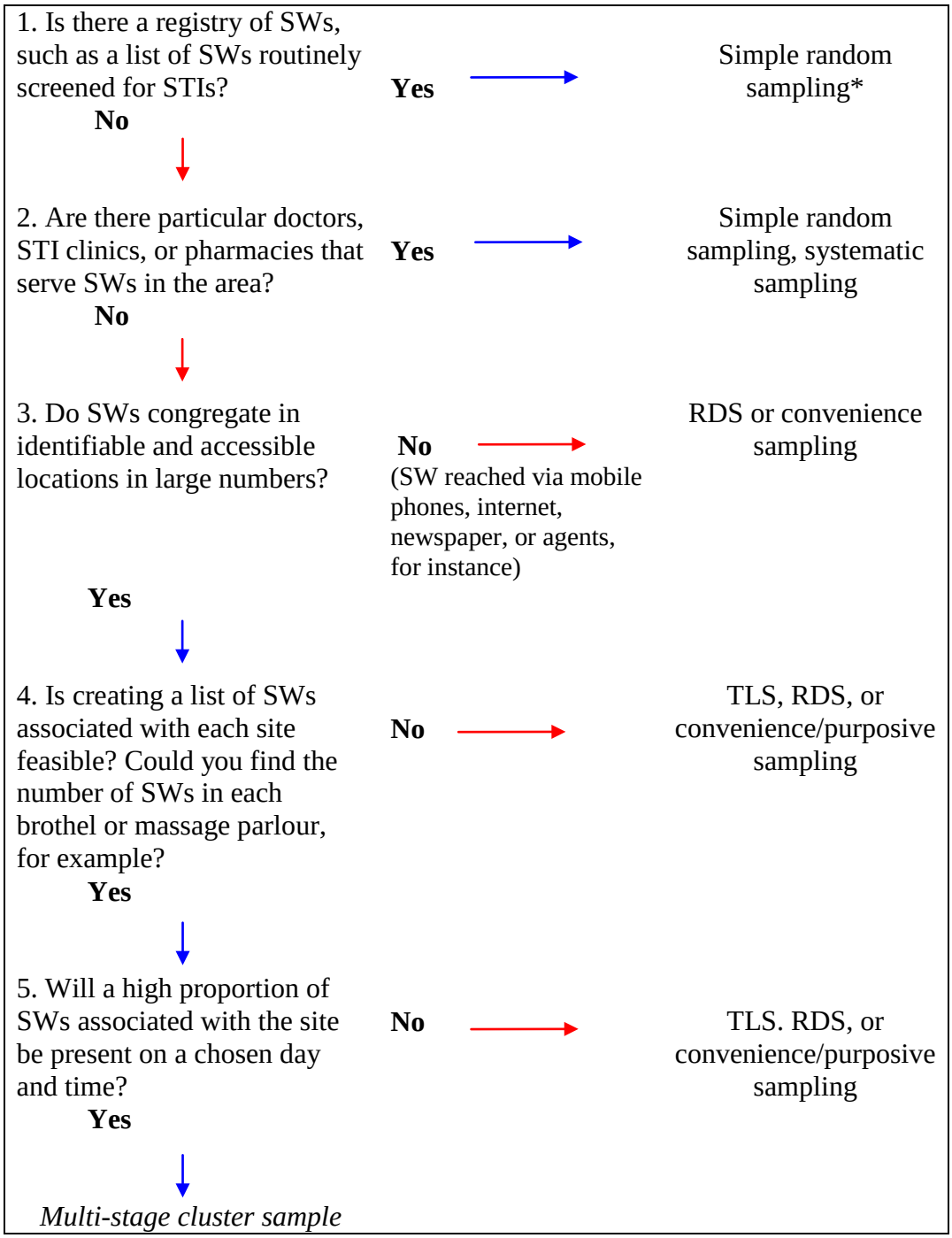
Depending on how SWs are organised and how easily they can be accessed, different sampling methods may be more or less possible. Several basic strategies for sampling hard-to-reach SW populations are:

- *consecutive sampling* via *unlinked anonymous testing* (UAT) for example, of MSW STI-clinic patients
- multi-stage cluster sampling
- *time-location sampling* (TLS)
- *respondent-driven sampling* (RDS); for example, to obtain a sample of transgendered SWs
- convenience/purposive sampling; for example, recruiting SWs from a *non-governmental organization* (NGO) that provides services to SWs.

Figure 2.2, on the next page, will help you select an appropriate sampling method for SWs in your area.

Selecting a Sampling Method, continued

Figure 2.2. Selecting sampling methods for SWs.



*Note that a simple random sample of SWs registered at an STI clinic may miss populations at high risk, such as indirect or highly mobile SWs.

Measures and Indicators

Biological measures

Measuring HIV sero-prevalence among SWs is an important part of surveillance. The high level of sexual risk among SWs also makes STI testing a useful and feasible *indicator* for surveillance. For a description of the available STI and HIV tests, refer to the WHO test kit evaluation programme at http://www.who.int/diagnostics_laboratory/evaluations/en/ . The biological measures to include will depend on the purpose of your surveillance activity:

- *Syphilis* testing is often the most efficient biological indicator because the standard tests can be done with the same serological specimen as used in HIV testing. The test is inexpensive and widely available.
- Accurate tests for *gonorrhoea* and *Chlamydia* are expensive and usually require a urine specimen.
- *Herpes simplex virus type-2* (HSV-2) testing is a marker for lifetime sexual risk, but it is less available. To be an indicator for sexual risk, the test needs to distinguish HSV-2 from HSV-1.
- *Trichomonas vaginalis* testing with positive results is a marker of sexual risk in women. As *T. vaginalis* is usually asymptomatic in men, it is not a good marker of sexual risk in men.

In areas where there may be suspected overlap between SWs and IDUs, biological markers may include *hepatitis C virus* (HCV) and *hepatitis B virus* (HBV).

Additionally, in some countries, HBV is often acquired perinatally or from child-to-child contact in household settings, and may therefore be a less accurate marker for injection drug use than in other regions.

Behavioural measures

Measuring changes in sexual behaviour among SWs helps explain trends in HIV and STI prevalence data. Among SWs, new behavioural trends may emerge rapidly, particularly when programmes and resources are targeted to promote safe behaviour in this group.

Several international organisations have sought to standardise a set of "core" or basic indicators of HIV risk among SWs. In 2001, the *United Nations General Assembly Special Session on HIV/AIDS* (UNGASS) developed indicators to include when conducting behavioural surveillance among SWs. These indicators were updated in 2005, and include:

- percentage of SWs who received HIV testing in the last 12 months and percentage that know the results
- percentage of SWs who correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV
- percentage of SWs reporting the use of a condom with their most recent client
- percentage of SWs reached by prevention programmes.

These basic indicators are mandatory to include when conducting behavioural surveillance among SWs in the region and should be supplemented with local measures of particular importance in your area (as determined by your formative assessment phase). These additional indicators may include:

- sex work venues
- number of clients
- number of non-client sex partners, types of sex partners
- condom use with non-client sex partners
- injecting drug use
- migration, mobility
- STI treatment-seeking
- history of imprisonment
- marital status
- basic demographic characteristics.

Reference to indicators

Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found at the websites listed in Unit 1 of this module.

Special Ethical Considerations

Because sex work is *stigmatised* and often illegal, SWs are a vulnerable population. Their participation in surveillance activities may place them at risk for harm and discrimination. These risks include:

- loss of *confidentiality*, or inadvertent identification as an SW
- inadvertent disclosure of HIV status
- negative reaction and backlash in response to publicised results
- physical abuse by their pimp or brothel manager
- loss of income.

Consider your ability to obtain true *informed consent* when SWs may be coerced to participate or not participate by their brothel managers, pimps, agents, or other handlers.

Assuring confidentiality

Confidentiality protects subjects from the negative consequences that may arise from participating in a study or survey. Be aware of any of your country's laws that may complicate participation. These may include:

- laws prohibiting sex work or sex work under a certain age
- laws prohibiting injection drug use
- laws prohibiting male-male sex
- laws requiring reporting of individuals with HIV infection.

People asked to participate in a survey or study should understand potential threats to their confidentiality. They should also understand the steps that the investigators will take to minimise these threats. Explaining these issues to them is part of the informed consent process.

Assuring confidentiality, continued

Steps you can take to minimise threats to confidentiality may include:

- conducting interviews with SWs in private settings
- keeping the names of the SWs separate from the data collected about them
- limiting access to any identifying information to authorised study personnel only
- keeping study documents in a locked, limited-access room
- requiring all staff to sign confidentiality forms and undergo training in research ethics.

Beyond surveillance

WHO has developed a HIV/AIDS sex work toolkit, intended to be used as a resource to guide the development and implementation of effective HIV interventions in diverse sex work settings. It outlines key steps and issues and provides links to many documents, manuals, reports, and research studies containing more detailed and in-depth information. You can access it here: http://www.who.int/hiv/topics/vct/sw_toolkit/en/

Summary

Sex work occurs in a wide range of settings and in a diverse group of sub-populations. SWs are at high risk for getting HIV and STIs from their clients and for transmitting them to other clients and their non-paying sex partners. Behavioural and HIV sero-surveillance among SWs plays a central role in all epidemic states. Depending on how SWs are organised and how easily they are accessed, different sampling methods may be more or less useful. As sex work is stigmatised and often illegal, special ethical issues must be considered when conducting surveillance among SWs.

Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of this unit. Make any changes you want to make. We will discuss the questions and answers in a few minutes.

Small group discussion

Get into small groups to discuss these questions:

1. Does your country conduct behavioural and/or sero-surveillance of SWs?

2. In your country, who are the gatekeepers of this population?

3. In your country, what methods are used to sample SWs?

4. In your country, what behavioural and biological measures have been used when conducting surveillance of SWs?

5. In the past five years, has the prevalence of HIV among SWs increased, decreased, or remained about the same?

Apply what you have learned/ case study (1)

Try this case study individually or in a group. We'll discuss the answers in class.

Formative Assessment among Female SWs in Port Marina, Globa

Part 1: Collecting information to plan surveillance activities/ formative assessment activities

Port Marina is a port city in Globa with a total population of three million. A large number of male workers from adjacent cities and provinces migrate to Port Marina for employment. It is also a transit point for sea-farers and truck drivers. Word has spread to the Ministry of Health from pharmacies and private doctors who have noticed higher prevalence of gonorrhoea, herpes, and trichomoniasis among their female clientele than among female clientele in other cities. Due to legal persecution and official denial of SWs' existence, sex work is a hidden trade; however, increasing prevalence of STIs has led healthcare providers to believe the population is growing and at risk for spreading HIV and other STIs. Very little work has been done with SWs and almost none with their client groups. There have been no attempts to develop SW programmes using the known best-practice approaches that include social development and empowerment. In Port Marina, no studies have been conducted that adequately explain the structure and functioning of the sex trade, the number of sex workers, the proportion of men in the population who access sex workers and their occupations, or other essential information for developing interventions.

In response, the HIV programme within the Ministry of Health would like to conduct HIV/AIDS behavioural surveillance among SWs in Port Marina. A meeting is held with a team of epidemiologists and social workers to plan for the survey. Because little is known about the population, however, they first decide to use formative assessment to lay the foundation from which data about SWs can be collected.

From their surveillance trainings, the team know the five steps to be conducted to meet the formative assessment goals: secondary data review, *key informant* interviews, *focus group* interviews, observation, and development of local prevention questions.

Part 1: Collecting information to plan surveillance activities/formative assessment activities, continued

The team discuss what they already know about SWs in Port Marina. Very little secondary data exist regarding commercial sex work either in Globa or the rest of the Middle East. Together, they try to find additional information and make a list of possible key informants and focus group participants. Their plan is to look for secondary data and meet with key informants in the city to find out more.

1. What are the goals of formative assessment?

2. Who are the possible key informants and participants for focus group discussions in Port Marina?

3. What types of questions does the team ask during their interviews?

Part 2: Finding secondary data and building key alliances with community networks involved with SWs

To obtain background information for designing a behavioural survey, the HIV programme team review several documents, including published literature, *grey literature*, reports from NGOs, clinic records of the public and private clinics, and reports from the police department. Grey literature is material that is not published in easily accessible journals or databases. Examples of grey literature include the following:

- programme evaluations
- government surveillance reports
- programme-planning documents
- abstracts of research presented at conferences
- unpublished theses and dissertations.

The HIV programme team also meet with a diverse set of key informants, such as pimps, bar owners, taxi drivers, private doctors, pharmacists, police, a couple of upper-class call girls, and NGO managers and outreach workers. Not only will they be able to help answer questions about sex workers, including the best ways to recruit SWs, and information about their social networks, demographic characteristics, and locations of operation, but they also are the community *stakeholders* of the behavioural surveillance survey. Before the interview, the key informants are taught about the need for and purpose of formative assessment to conduct behavioural surveillance. Afterward, interviews are conducted using open-ended questions, and you seek verbal assurance of their willingness to

collaborate with the HIV programme team. Their support will go a long way to ensure that the activities are acceptable to the broader community once data collection begins.

Next, the HIV programme team put together four focus groups: one each for SWs, private doctors, law enforcement, and some truck drivers and fisherman. After obtaining informed consent from the participants, the team are able to identify a local vocabulary to be used in the questionnaire, key people who have access to SWs, locations where they may be reached and interviewed, possibilities for incentives, information about their social networks, population-specific health risk behaviours, and options for conducting the surveillance.

Using information from the formative assessment, the HIV programme team compile their information and maps available health services, pharmacists that SWs feel more comfortable using, and NGOs operating in the area. Much information is still unknown, as the sex industry is very clandestine and dangerous for those who participate, and people remain suspicious of any investigations. Through the information collected, the HIV programme team find that the sex trade is operated primarily using mobile phones and text messaging. Private practitioners are able to estimate the number of sex workers that they see, because sex workers frequently visit them for treatment of STIs and other ailments, yet not all sex workers go to these special STI clinics and many come from varying socio-economic strata. The HIV programme team hear of a few brothels in the city and observe some street-based sex work; however, they decide to concentrate on the seemingly larger and more hidden population of sex workers who use mobile phones to market themselves.

First, the team decide to put a large effort into estimating the population size of mobile phone–using SWs in Port Marina. This task is difficult because so little is known about SWs, the population seems dispersed and difficult to access, and there is a limited social network.

1. What are the possible approaches to estimating population size among SWs in Port Marina?

2. Why does the team decide to concentrate on estimating the population size of the mobile phone–using SW population in Port Marina?

Part 3: Estimating population size

Because mobile phones seem to be the predominant mode of communication within the sex trade, the HIV programme team decide to estimate the size of the mobile phone–using SW population in Port Marina. Estimating the population size of SWs will help determine the sample size for the behavioural surveillance survey and plan for any interventions that may follow pending the results. The team decide to use the *capture-recapture method* for estimating population size.

Capture-recapture is a technique used to estimate numbers of persons in a target population. According to this method, two or more lists containing individuals in common can establish the number of individuals missing from both, thereby estimating the total population of interest.

The team conduct an informal interview with 100 men in various hotel lobbies, after obtaining their consent, to ask how much text messaging spam they received during the week prior and how much different spam they received from potential SWs. The spam could be any type of text messaging, including "Bluetooth" messages of SWs that are in the area. The men can count the number of messages by looking back in their mobile phone inbox. The interviewers compile a list of the phone numbers from the spam received. A week later the team repeat the interviews and the two lists are compared (Table 2.3, below). By establishing the number of individuals missing from both lists, the team can make an estimation of the total number of SWs in the city. The phone numbers possibly could be used in the future as a way to access the SWs for sampling purposes.

Table 2.3. Estimated number of SWs in Port Marina, Globa

		Week 1 List		
		Present	**Absent**	**Total**
Week 2 List	**Present**	310_{11}	515_{01}	825_{B}
	Absent	430_{10}	n_{00}	
	Total	740_{A}		N

Estimated Values	**Formula**	
Individuals missing	n_{00}	$n_{01}(n_{10})/n_{11}$
Total Population	N	$n_{A}(n_{B})/n_{11}$

3. How many mobile phone–using SWs does the team estimate are in Port Marina?

4. What are the limitations of this method, in terms of using cell phone numbers?

Part 3: Estimating population size, continued

5. What are the assumptions of capture-recapture and are they met?

6. Prior to conducting formative research, what did the team need to do to make the study ethical and have a chance of publishing their findings?

7. How did the HIV programme team engage the different stakeholders for this activity?

Part 4: Obtaining institutional review board approval

The team estimate that there are about 1970 mobile phone–using SWs in the city. This information, however, is limited because some SWs may have multiple cell phones. Nonetheless, this is the best information the team have and from it they can estimate their sample size for the behavioural surveillance. The capture-recapture assumptions were met in this activity: 1) the population is closed, meaning SWs would not be migrating in and out of the city in a week; 2) the sources of data are independent, meaning new lists were made each week of phone numbers only captured within the past week from the same hotels; 3) the SWs had the same chance of being listed in each data source; and 4) individual phone numbers were matched. Using the phone numbers they have collected and the alliances they have made, the team are well on their way to developing the surveillance protocol.

Prior to conducting their formative research activities, the HIV programme team went through a series of steps to obtain approval for their research before they began interviewing people. Because Globa does not have an *institutional review board*, they developed a national ethics research committee to protect the rights of SWs and anyone participating in research. The committee put together an application, which was composed of much the same material as described in previous sections of this case study, and sent it to their ethics committee.

8. What special ethical considerations must be considered for formative research?

Part 5: Epilogue

The HIV programme team submitted their application to the ethics committee and obtained approval to conduct their formative research activities. They discussed in the application their objectives and how informed consent would be obtained and included a sample consent form. They mentioned the benefits of the study and the risks to participants, although these risks were quite minimal, and discussed their entire methodology.

During a debriefing with community stakeholders, including those who participated in key informant interviews and representatives from donor organisations, the team discussed the results and their next steps. The team were able to write up the results from their formative research and submit them for publication in a peer-reviewed journal because very little information exists regarding sex work in Globa. They also began writing the protocol for their behavioural surveillance survey.

Their findings assisted them with choosing a sampling approach. Based on the disassociated network of the SWs and their hidden nature, the HIV programme team decided on a convenience sampling approach. They also realised it was possible to do a biological and behavioural survey after discussions with key informants and focus group participants. They found that the biological component of the survey would offer SWs some care and treatment, if needed, and provide them with referrals to healthcare options in the area.

With the help of focus groups, the HIV programme team also began developing the questionnaire that they would use in their behavioural surveillance survey. Preliminary drafts of the questionnaire were piloted successfully.

The team are well on their way to conducting the first behavioural surveillance survey among sex workers in Globa.

Apply what you have learned/ case study (2)

Try this case study individually or in a group. We'll discuss the answers in class.

Behavioural Surveillance among Brothel-based SWs In Abuport, Globa

Part 1: Collecting information to plan surveillance activities

Abuport is a port city in Globa with a total population of 10 million. A large number of male workers from adjacent cities and provinces migrate to Abuport for employment. It is also a transit point for sea-farers and truck drivers. In response to a high demand, there is a sizeable commercial sex industry operating in the city. In 2003, there were an estimated 20 000 to 30 000 SWs in Abuport. It is believed that most of the sex trade in Abuport is brothel-based.

The annual HIV sero-surveillance data, published by the National AIDS Programme, Ministry of Health, Globa, indicates that the HIV prevalence among SWs has remained high in the past five years. Recently, the Kate Foundation, a philanthropic international agency, awarded a five-year grant of 2 million USD to Abuport Municipal Corporation for implementing prevention interventions among SWs. Annual instalments of the grant will be released after the performance of the prevention programme has been reviewed. The Kate Foundation has allocated 15% of the total grant for surveillance and monitoring and evaluation activities.

The Commissioner of Public Health, Abuport City, directs the HIV programme manager to develop a package of evidence-based interventions to reduce HIV transmission among SWs.

The HIV programme manager decides to undertake a behavioural survey among brothel-based SWs in Abuport. He holds a meeting with his team of epidemiologists and social workers to plan for the survey.

1. What information is required for planning the survey?

2. How will the Abuport HIV team obtain this information?

Part 2: Building key alliances with community networks involved with SWs

To obtain background information for designing a behavioural survey, the HIV team review several documents, including published literature, grey literature, reports of NGOs, clinic records of the public and private clinics and reports from the police department. Grey literature is material that is not published in easily accessible journals or databases. Examples of grey literature include the following:

- programme evaluations
- government surveillance reports
- programme-planning documents
- abstracts of research presented at conferences
- unpublished theses and dissertations.

Interviews of key informants are also conducted using open-ended questions. Several key informants are contacted, including pimps, bar owners, auto rickshaw drivers, police, and NGO managers and outreach health workers. The HIV team collect information on how the brothel-based sex trade is operated, the location and number of brothels, the number of SWs in each brothel, the business hours of SWs, health services available in the area, and NGOs operating in the area.

Using information from formative research, the HIV team map the brothels in Abuport. It is noted that 80% of the brothel areas are concentrated in the southern part of the city, named Southport. There are approximately 80 brothels in Southport. On average, there are 30 sex workers in each brothel. As commercial sex work in Globa is illegal, the brothel owners allow limited visibility and mobility of sex workers. Although there are several public health clinics in the area, these remain largely underused due to the lack of availability of drugs. SWs frequently visit private practitioners for treatment of STIs and other ailments.

Because the majority of the brothels are concentrated in Southport, the HIV programme manager decides to first undertake a behavioural survey among SWs in Southport. The HIV team realise that to access SWs, it is necessary to enlist support of stakeholders.

3. Who are the key stakeholders and community groups with whom it is necessary to build alliances?

4. How will the HIV team engage the different stakeholders?

Part 3. Choosing approaches to behavioural survey

The HIV team meet with NGO managers, brothel owners, agents, pimps, madams, auto drivers, hotel managers, bar owners, and the police in the area.

A briefing meeting is organised at which the HIV programme manager informs the stakeholders about the need for and purpose of the behavioural survey. The expected outcome of the survey is explained to the audience.

With verbal assurance of the cooperation of the stakeholders, the HIV team are now ready to move to the next step.

5. What are the possible approaches to conducting a behavioural survey among SWs in Southport?

6. What are the advantages and disadvantages of each approach?

Part 4. Choosing a sampling approach

The Abuport HIV team have two options: 1) to undertake a community-based survey at the workplace of SWs (for example, brothels); or 2) to undertake an institutional survey at the public health clinic where SWs access treatment for STIs.

The team weigh the pros and cons of each approach. It is less expensive and logistically easier and quicker to use an institutional approach. The team, however, feel that the reach of the public clinics is limited, as nearly three-fourths of the SWs are using services from private practitioners in the area. It is more expensive to undertake a community-based survey, but the findings of the survey will be more representative of all SWs in the brothels.

Given the availability of adequate resources, the cooperation assured by the stakeholders, and the strengths of a community-based survey, the team decide to undertake a community-based, cross-sectional survey of risk behaviours among brothel-based SWs in Southport.

7. What sampling design can be used to select representative respondents for the interview?

8. What would be an adequate sample size to detect an increase in consistent condom use (defined as use of condoms during every episode of vaginal intercourse during the preceding three months) with clients among SWs from 20% in the current year to 35% if the survey is repeated in two years? Refer to Annex 1.1. Table 1. Sample Size Options.

Part 5. Collecting behavioural data

The most conservative sample size to detect an increase of 15 percentage points (20%-35%) in the proportion of SWs who reported consistent condom use (with 80% power of detecting a change of this magnitude at the 95% confidence level significance), is 274 SWs per survey year. The sample is increased by 10% to account for non-response, refusal, and other non-participation. Thus, the final sample size is rounded to 300 per survey year.

The surveillance team are able to obtain a reasonably complete listing of brothels in Southport with the approximate number of SWs in each brothel, which helps in constructing a sampling frame. A two-stage cluster sampling design is used. In stage I, 20 brothels are randomly selected using a list of random numbers. In stage II, a fixed number of 15 SWs are selected in each brothel by random sampling.

9. What behavioural variables should be collected?

10. What special ethical considerations must be considered for this surveillance activity?

Part 6. Analysing and disseminating data

Note: Although analysis and dissemination of data are not covered in this module, it is expected that participants have a basic understanding of these activities.

Trained interviewers contact SWs at the selected brothels during non-business hours. They explain the purpose of the study and obtain verbal consent. Confidentiality is assured. Interviews are conducted in privacy and in a non-coercive manner. Personal identifiers are not collected.

The interviewers administer a pre-tested, semi-structured questionnaire to the selected SWs to assess their sexual risk behaviours and practises. Variables collected are socio-demographic variables, including age and formal schooling; duration of engaging in sex work; number of clients entertained per week; risk perception of acquiring HIV; history of a vaginal discharge or ulcer in the past year; STI treatment-seeking; STIs correctly treated; consistent condom use; onsite availability of condoms; reasons for non-use of condoms; and condom negotiation practises.

Data are entered in a database, cleaned, and analysed using STATA. A summary of the results is presented to the Abuport City Public Health Commissioner:

- A total of 289 SWs were interviewed. The mean age of respondents was 30.9 years; 20% were non-literate and 44% had a primary

Part 6. Analysing and disseminating data, continued

education. On average, each SW had entertained 13 clients in the previous week.

- Nearly all respondents had heard about HIV/AIDS and 92% mentioned that consistent use of condoms could prevent transmission of HIV and other STIs.
- Among the respondents, 22% reported having had a vaginal discharge or genital ulcer in the past year; of these, 63% sought care from a private practitioner, 5% sought care from public clinics, and the remainder ignored their symptoms.
- Among the respondents, 64% had used a condom with their most recent client. Refusal by clients was the most common reason for non-use of condom; 86% reported insisting that their clients must use condoms. Respondents reported encountering clients who refused sex without a condom, 48% successfully renegotiated condom use, 30% increased fees and had sex without a condom, and the remaining 22% refused sex.
- Only 23% of the respondents reported consistent condom use with regular partners.
- Of those who had used a condom with their most recent client, 12% had obtained it from the client, 32% from a peer or an NGO worker, and the others from a pharmacy. Only 37% of respondents reported having a condom at the time of the interview.

11. What interventions should be initiated based on these results?

12. How would the HIV programme manager disseminate the results of the survey?

Part 7. Epilogue

Based on the community survey, brothel-based SWs in Southport were highly at risk of acquiring and transmitting HIV. SWs had a high partner turnover; a large proportion had untreated STIs, and condom use was low with clients and even lower with non-paying partners. Inadequate condom negotiation skills and lack of onsite condom availability resulted in low condom use. Urgent targeted interventions were needed to increase safe sex practises among SWs in Southport.

Based on these findings, the public health commissioner of Abuport directs the HIV programme manager to initiate the following interventions:

- engage peers and NGO outreach workers to educate SWs about the need for consistent condom use with clients and regular partners
- conduct workshops to improve SWs' condom negotiation skills
- distribute condoms to SWs through peers and NGO workers

Part 7. Epilogue, continued

ensure a regular supply of STI antimicrobials at public health clinics and train health workers at public and private health clinics in correct STI management.

The HIV survey team organise a two-hour debriefing of stakeholders, including representatives of the Kate Foundation and other donors, NGO managers and staff, and some brothel owners and sex workers. The HIV manager presents the findings of the survey, as well as the planned interventions. Goals are set to gauge the reach and impact of these interventions in two years' time. A full report of the survey is posted on the website of the Abuport health department and distributed to a wide audience.

NOTES

Unit 3

Injecting Drug Users

Overview

What this unit is about

This unit describes the background and special considerations associated with conducting HIV behavioural and sero-surveillance among injecting drug users (IDUs). The unit includes a case study highlighting special issues in conducting surveillance among IDUs.

Warm-up questions

1. List two examples of blood-to-blood (or parenteral) transmission of HIV.

   a.
   b.

2. Which of the following sampling methods can be used for surveillance among IDUs?

   a. time-location sampling
   b. multi-stage cluster sampling
   c. convenience sampling
   d. simple random sampling from a drug treatment clinic registry

3. List two organisations with which you can form alliances as you develop your HIV surveillance system for IDUs.

   a.
   b.

4. List two interventions that can help reduce HIV transmission among IDUs.

   a.
   b.

5. What are the ethical issues you must consider when conducting surveillance among IDUs?

Introduction

What you will learn

By the end of this case study, you should be able to:

- describe special considerations associated with doing HIV surveillance among IDUs
- describe options for sampling and surveillance methods among IDUs
- list key biological and behavioural measures used for tracking the HIV epidemic among IDUs
- describe the special ethical considerations associated with conducting HIV surveillance activities among IDUs.

Background

Definitions

This unit focuses on the special issues in conducting *behavioural surveillance* and HIV *sero-surveillance* among *injecting drug users* (IDUs).

Drugs injected by IDUs may include:

- opiate derivatives, such as heroin
- cocaine
- methamphetamine
- other sedative and hypnotic drugs
- combinations of these drugs.

Most of these drugs are highly addictive and expensive; obtaining and injecting drugs can dominate the lives of these people.

Drugs can be injected by different routes, including the following:

- intravenously (into a vein)
- intramuscularly (into a muscle)
- subcutaneously (below the skin)
- intradermally (into the layers of the skin)

The risk of HIV infection is greatest with intravenous injection, but the other types of injection also carry high risks of HIV transmission. Persons who inject drugs may move in and out of injecting behaviours, and at times, may use drugs by sniffing or smoking.

Definitions, continued

Non-injectable drug use, such as smoking marijuana, ingesting sedative-hypnotic drugs, inhaling cocaine, sniffing glue, and drinking alcohol cannot lead to HIV transmission directly. These drugs can contribute indirectly to the problem of HIV through the necessity for sex work to acquire funds to buy the drugs or through poor decision-making about sexual risks. This poor decision-making is also called *disinhibition*.

If the goal of your surveillance system is to track HIV among drug users who do inject, you must distinguish IDUs accurately from other drug users. Screening for injection may occur at the facility level; at de-addiction clinics specifically for IDUs, for example; or by trained interviewers. Methods for identifying true injectors include physical examination for track marks and other signs of injection or detailed interviews on how drugs are prepared for injection.

WHO, UNODC and UNAIDS developed a technical guide for countries to set targets for universal access to HIV prevention, treatment and care for injecting drug users. It can be accessed here for more information: http://www.who.int/hiv/pub/idu/idu_target_setting_guide.pdf

Role of IDUs in the HIV epidemic

IDUs are at high risk for HIV infection because of the practise of sharing needles and syringes to inject drugs. Every time a needle or syringe is shared, the person injecting also may inject a small amount of the previous user's blood that is still in the barrel of the needle or tip of the syringe. This can be a very efficient means of transmitting a number of viruses, including HIV, *hepatitis B* (HBV) and *hepatitis C* (HCV). *Parenteral transmission* is blood-to-blood transmission, such as transmission through:

- transfusion of blood
- transfusion of blood products, such as anti-haemophiliac factors
- needle stick injuries, such as might occur in healthcare personnel
- re-use of needles in medical settings, for blood donation and other procedures
- organ transplantation
- injection of illegal drugs intravenously, intramuscularly, subcutaneously, or intradermally.

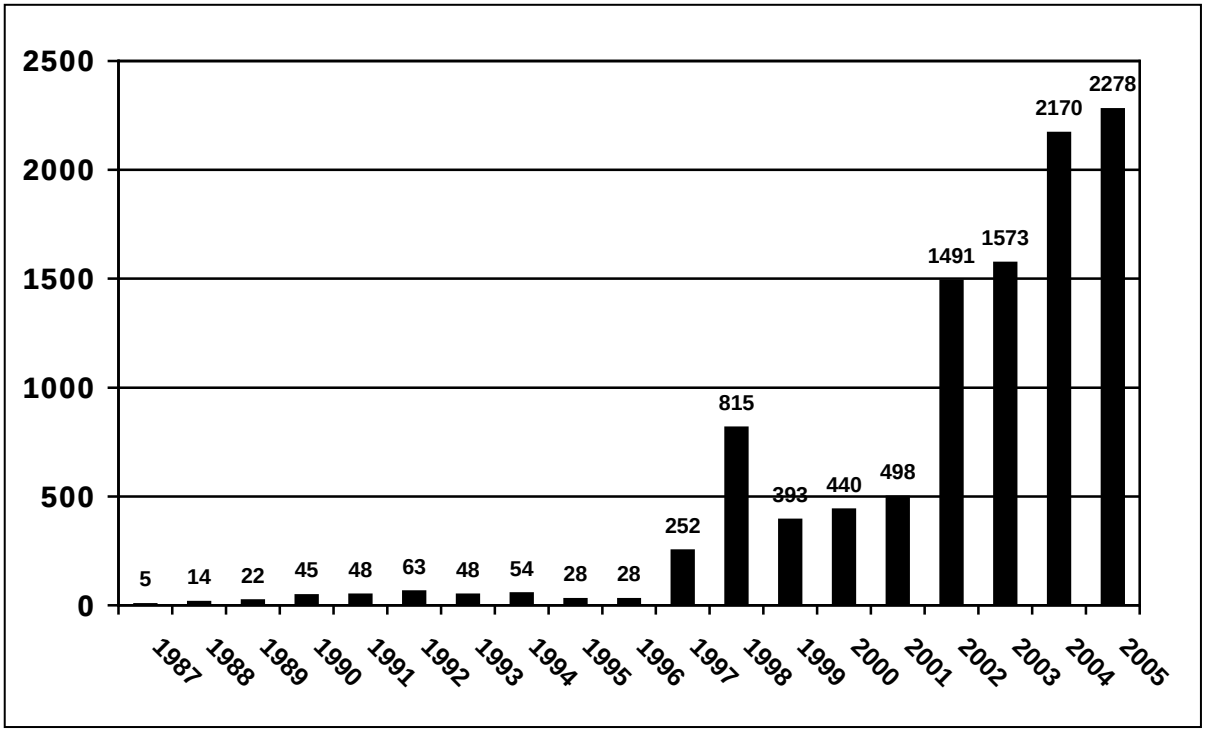
Further, IDUs also are at risk for sexual transmission of HIV, through sex work and through sex with their regular and non-regular partners.

According to the United Nations Office on Drugs and Crime (UNODC), around 10% of all new HIV infections worldwide are due to injecting drug use. Data from Iran suggest that nearly 85% of 13 000 HIV cases reported

Role of IDUs in the HIV epidemic, continued

between 1987 and 2005 are attributable to injection drug use.

Figure 3.1 Identified HIV cases by year in Iran (total ~ 13 000).



Source: Iranian Center for Disease Management (March 2006)

Discussing the figure

Looking at Figure 3.1, answer the following questions:

a. What are some of the factors that may have contributed to the apparent increase in identified HIV cases in Iran between 1995 and 2005?

b. Has your country experienced similar increases in recent years?

c. What might have caused the 'spike' in cases in 1998? What are the related implications for interpretation?

In most regions of the world, injecting drug users are a *hard-to-reach population* because drug use is illegal and *stigmatised*. The need for money to buy drugs can also lead to crime and sex work, thus further marginalising IDUs. The desire to remain hidden from authorities also makes IDUs hard to reach for prevention programmes and for conducting surveillance activities.

Prevalence of HIV among IDUs

Injection drug use is one of the main modes of HIV transmission in virtually all parts of the world, particularly in industrialised and middle-income countries. In some countries, injection drug use has emerged as one of the strongest drivers of HIV infection. In many countries with *low-level* and *concentrated epidemics*, HIV has spread most rapidly among IDUs.

Historically, regions where heroin trafficking takes place can have explosive HIV epidemics once the disease is introduced.

There are three major routes of opiate production and trafficking which supply three distinct markets, namely:

• Afghanistan supplying neighbouring countries, the Middle East, Africa and, in particular, Europe
• Myanmar/Lao PDR supplying neighbouring countries, in particular China, and Oceania (mainly Australia)
• Latin America (Mexico, Colombia, Guatemala, and Peru) supplying North America, in particular the United States (UNODC).

Prevalence of HIV among IDUs

According to UNAIDS, injecting drug use also has contributed substantially to the HIV epidemic. The prevalence of HIV infection among IDUs varies by country and region, including the following examples:

- In Mauritius, approximately three quarters of the HIV infections diagnosed in the first six months of 2004 were among IDUs (Sulliman & Ameerberg, 2004, UNAIDS)
- In various studies, almost half of the IDUs tested in Mombassa and Nairobi, Kenya were found to be HIV-positive, as were 26% in Zanzibar, and 28% in South Africa (Ndetei, 2004; Odek-Ogunde, 2004, UNAIDS)
- In 2005, a national survey in Myanmar found an HIV prevalence of 43% among IDUs (2006 UNAIDS Epidemic Update)
- In the Caribbean, injecting drug use is responsible for a minority of HIV infections, contributing to the spread of HIV only in Puerto Rico and Bermuda (UNAIDS).

Prevalence of HIV among IDUs, continued

- In a HIV sentinel survey in six Ukrainian cities in 2007, HIV prevalence among IDUs ranged from 10% in Lugansk to 13% in Kieve, and 89% in Krivoi Rog (Ukrainian Institute for Social Research et al., 2007a, UNAIDS)
- In Marvdasht, Iran, 85% of IDUs said they had used drugs in prison, and 19% said they had used non-sterile injecting equipment there (Day, 2006).
- According to UNAIDS, IDUs constituted 91.7% of the registered 4439 HIV/AIDS cases in Libya in 2001, 34% in Tunisia in 1999, and 18.4% in Algeria in 2000.
- The use of non-sterile injecting drug equipment in Uruguay accounts for 18% of HIV infections (National AIDS Program Uruguay, 2007, UNAIDS).
- By the end of 2006, among the 1070 cumulative HIV cases in Kyrgyzstan with a known route of transmission (98%), 77% were reported to be infected through injecting drug use. According to a behavioural survey from Bishkek in 2000, 14% of IDUs use sterile syringes, 99% take drugs from common containers, and 35% use the same syringe more than 20 times. (www.euro.who.int/aids/ctryinfor/overview/20060118_25)

Role of IDUs in surveillance and bridges with other populations

In countries with substantial numbers of IDUs, HIV may first appear within the IDU population, spread rapidly, and reach the highest prevalence. IDUs may be further connected to other populations at risk for HIV. In particular, a large proportion of both male and female IDUs may engage in sex work to support their addictions. In various surveys, for example, more than 40% of IDUs in Algeria, 36% in Egypt, and 33% in Lebanon said they had either bought or sold sex in the previous month (Ministere de l'Enseignement Superieure et de la Recherche Algeria, UNAIDS & UNODC, 2006; Elshimi, Warner-Smith & Aon, 2004; Khoury & Aaraj, 2005). Other IDUs may have sexual partners who are not IDUs. Finally, the mothers of HIV-infected children are often IDUs or partners of male IDUs in countries with low-level and concentrated epidemics.

IDUs overlap with many other *most-at-risk populations* (MARPs) covered in this module. IDUs are found among *men who have sex with men* (MSM), prisoners, street children, and *sex workers* (SWs). Therefore, HIV surveillance of IDUs can serve to monitor the reach, acceptance, and effectiveness of intervention programmes for both IDUs and other populations at high risk.

An example

During the past 5 to 10 years, the number of HIV/AIDS cases reported in the Ukraine and the Russian Federation has risen dramatically due to a sharp increase in injection drug use and subsequent spread among heterosexually active IDUs. In this region, IDUs constitute a key *bridge* to the general heterosexual population, especially to young females. Genotyping and sequencing of the reverse transcriptase and protease gene regions performed on over 200 *HIV-1* strains by Sanchez et al between 2000 and 2003 confirmed that the sub-type found in the general heterosexual population was similar to the sub-type found among IDU *networks* in the region.

Conducting a Formative Assessment

Identifying points of access

As IDUs tend to form close-knit communities, HIV prevalence may differ considerably in places that are relatively close within a given country, or even within a given city. Identifying points of access and forming alliances with organisations and persons trusted by IDUs will help you understand more fully the culture and diversity of IDUs in your area. Due to the illegal and stigmatised nature of injecting drugs, locating and accessing this population can be difficult. Individual IDUs may be reluctant to participate in surveillance activities if they fear arrest and criminal charges. A useful starting point for gaining access to IDUs is to speak with people who deal with IDUs through the healthcare system, through prevention programmes, and through the justice system. In addition, working with former and current IDUs can guide you to the places where IDUs can be found and into the social networks of different groups of IDUs. People to contact include the following:

- former and current drug users
- staff of needle-exchange programmes
- staff of *non-governmental organizations* (NGOs) working with IDUs
- law enforcement, police, and criminal justice staff
- staff of drug rehabilitation centres and methadone centres
- social welfare and service organisations
- drug dealers (if possible)
- staff of healthcare institutions that provide care for IDUs, such as hospital casualty departments who may see, for example, large numbers of drug overdoses and wound infections.

These same people and organisations also can later assist with implementing surveillance activities. Former IDUs, for example, can be hired and trained as recruiters or interviewers. Hiring former IDUs gives you the added advantage of using their experience to distinguish true IDUs from non-injecting drug users. *Alliances* with institutions dealing with IDUs also may assist with referrals to treatment or with minimising police interference during field activities.

In different countries, drug treatment centres may be referred to as de-addiction centres or clinics, detention centres, or recovery centres. In this module, when referring to these types of centres, we will use the general term “drug treatment centre.”

Conducting ethnographic mapping

Ethnographic mapping entails the creation of a comprehensive description of the IDU population with regard to:

- the places where IDUs can be found
- time periods of high- and low-volume drug use
- the types of drugs used.

This comprehensive description is used broadly to guide where and when IDUs can be found for recruitment to surveillance activities, and which sub-populations can be found in different areas. More specifically, detailed ethnographic mapping can be used to produce a *sampling frame* or comprehensive roster representing the IDU population in your area. This sampling frame provides the basis for some *probability sampling* methods, such as *time-location sampling* (TLS) and *multi-stage cluster sampling*.

Consider where to find IDUs

In many countries, injection drug use is considered a mental health issue. Thus, IDUs may be found in large numbers at a variety of facilities:

- drug treatment clinics, including de-addiction and methadone maintenance clinics
- needle-exchange programmes
- jails or prisons
- social service organisations serving IDUs or IDU drop-in centres run by NGOs
- hospitals
- mental health facilities.

Outside of facilities, the places where IDUs can be found in relatively large numbers can be identified through *key informants* from the institutions listed and through police reports of drug-related arrests. Other locations where IDUs may be found include:

- under bridges and flyover passes
- abandoned buildings
- streets and alleys
- graveyards
- garbage dumps
- gardens and parks
- beaches.

Check at drug treatment centres or methadone maintenance programmes

Surveillance in IDUs historically has been based at drug treatment centres and other centres of care, such as the accident and casualty departments of hospitals. This is because these facilities are places where IDUs are easily accessed. Often, *sentinel surveillance* using *unlinked anonymous testing* (UAT) of patients is used. Other countries have relied on IDUs who have been arrested and imprisoned, also using the UAT or mandatory testing approach. Neither of these populations, however, is likely to represent the important group of IDUs who are not arrested or do not seek treatment. Sometimes, targeted intervention sites provided by NGOs are used for collection of data using a *voluntary counselling and testing* (VCT) approach.

The illegal nature of injecting drug use means that those most at risk may avoid the official healthcare system altogether. Therefore, they will be under-represented in surveillance based at drug treatment centres and other sites where surveillance is implemented. Basing measurement on IDUs presenting for treatment at rehabilitation clinics or among those arrested for drug-related offences may provide highly biased information. These sites may not give a clear picture of behaviour or infection in the larger population of IDUs. Because of this, *community-based sampling* approaches for IDUs are preferred.

Selecting a Sampling Method

A number of sampling techniques have been used by researchers to access hidden or hard-to-reach populations, such as IDUs. These have included:

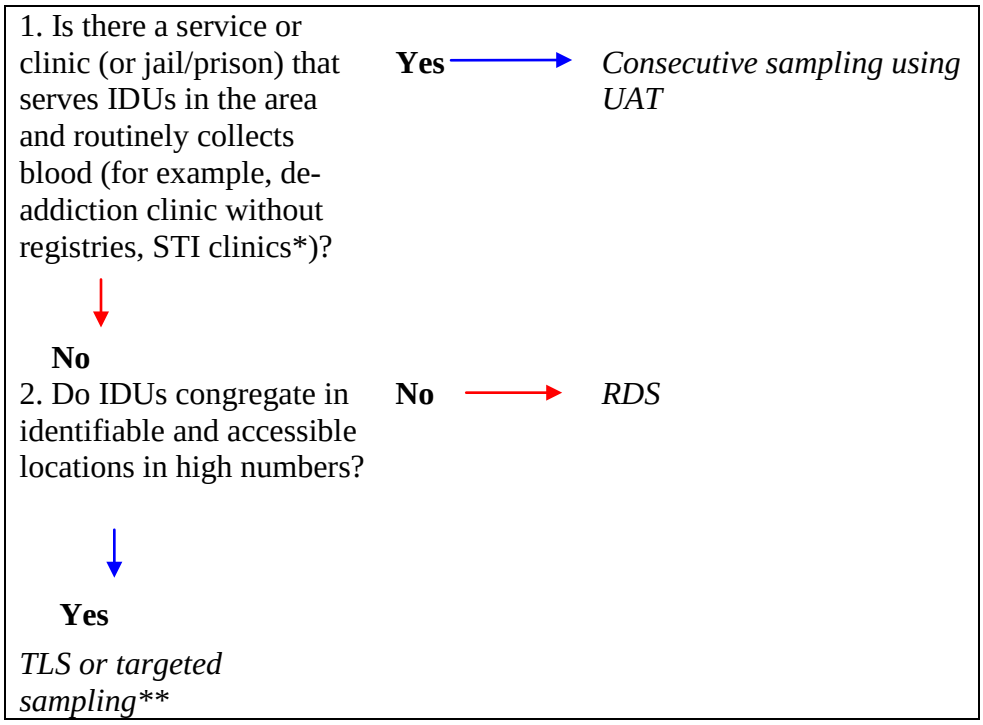
- *consecutive sampling* at treatment facilities, using UAT
- consecutive sampling in jails and prisons, using UAT
- *respondent-driven sampling* (RDS)
- time-location sampling (TLS)
- non-probability sampling methods, such as *snowball sampling*.

These sampling methods all have advantages and limitations. The information gathered during your formative assessment will help you decide which sampling methods are feasible and appropriate.

Selecting a Sampling Method, continued

Figure 3.2 will help you select an appropriate sampling method for IDUs in your area.

Figure 3.2. Decision tree for selecting sampling methods for IDUs.



* Not all IDUs may enter these facilities.
** Targeted sampling may be used when, through formative assessment, you have determined the relative size of the sub-populations of IDUs in the different areas. If, for example, you know that 35% of IDUs in your area are youth who congregate near the beach, 30% are MSM in the city centre, and 35% are professional artists/designers who congregate in the theatre district, you can target your sampling to locations in the neighbourhoods in these proportions.

Safety factors

Recruiting and interviewing IDUs in drug use areas or other dangerous neighbourhoods may compromise the safety of interviewers. Consider the safety of the data collectors when determining what sampling design is most appropriate for your situation. If, during your formative assessment, you find that particular locations or times are too dangerous for data collectors, some sampling designs, such as TLS, may not be feasible.

Measures and Indicators

Biological measures

Measuring HIV sero-prevalence among IDUs is an integral component of surveillance. Biological measures that also serve as markers for risk of parenteral infection include:

- Anti-hepatitis B core antigen (anti-HBc) is a non-specific marker of acute, chronic, or resolved HBV infection. Anti-HBc usually is found in chronic HBV carriers, as well as those who have cleared the virus, and it usually persists for life.

- Hepatitis B surface antigen (HBsAg) is a marker of infectivity. Its presence indicates either acute or chronic HBV infection. In some people, particularly those infected as children or with weak immune systems, such as people with AIDS, chronic infection with HBV may occur and HBsAg remains positive.

- Hepatitis C antibody is a non-specific marker of acute, chronic, or resolved HCV infection. These tests cannot tell if people still have an active viral infection, only that they were exposed to the virus in the past.

- IDUs also are at risk of HIV through sexual behaviour. Biological markers for STIs may be considered in surveillance for IDUs.

For a description of the available STI and HIV tests, refer to the WHO test kit evaluation programme:
(http://www.who.int/diagnostics_laboratory/evaluations/en/)

Limitations

In some countries HBV is often gotten perinatally or from child-to-child contact in household settings and may be less of a marker for injection drug use than in other regions.

In areas where both HBV and HCV are endemic, a biological marker for parenteral exposure may not be available. Before including HBV and HCV as markers for injection drug use in your surveillance activity,

Limitations, continued

determine the current and historical modes of HBV and HCV transmission in your country.

Behavioural measures

Measuring changes in injection and sexual behaviour among IDUs helps explain trends in HIV and STI sero-prevalence data. The sharing of needles and syringes is a very efficient means for the parenteral spread of HIV infection. The probability of HIV infection among IDUs is proportional to the frequency of needle- and syringe-sharing. Some drugs may result in more frequent injection than others. Cocaine and methamphetamine injection, for example, may become more frequent than heroin injection in many cases. Consequently, the type of drug determines the frequency of injection and, hence, the risk of HIV infection.

In broad strokes, behavioural surveillance among IDUs attempts to measure:

- the frequency of needle- and syringe-sharing
- the frequency of unprotected sex.

Several international organisations have sought to standardise a set of "core" or basic *indicators* of HIV risk among IDUs. In 2001, the *United Nations General Assembly Special Session on HIV/AIDS* (UNGASS) developed indicators to include when conducting behavioural surveillance among IDUs. These indicators were updated in 2005 and include:

- the percentage of IDUs who avoid sharing injecting equipment
- the percentage of IDUs who received HIV testing in the last 12 months and who know the results
- the percentage of IDUs reached by prevention programmes
- the percentage of IDUs who both correctly identify ways of preventing the sexual transmission of HIV and reject major misconceptions about HIV transmission.

Behavioural measures, continued

These basic indicators are mandatory to include when conducting behavioural surveillance among IDUs and may be supplemented with local measures of particular importance in your area, as determined by your formative assessment phase. Additional indicators may include:

- injecting locations, such as graveyards
- frequency of injections
- types of drugs injected
- people with whom IDUs share needles and syringes
- size of social network
- condom use
- history of incarceration
- history of sex work
- contact with SWs.

Reference to indicators

Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found at the websites listed in Unit 1 of this module.

Indicators recommended by international bodies will not necessarily capture all behaviours relevant to your area. Some questions will be for local use only, such as questions about exposure to specific prevention programmes or to assess particular risky practises. The formative assessment phase should be used to determine the local questions of greatest relevance to the epidemic in your area. In addition, the wording of the indicators should be translated and field-tested in your local languages.

Special Ethical Considerations

Because drug use is stigmatised and usually illegal, IDUs are a *vulnerable population*. Their participation in surveillance activities may place them at risk for harm and discrimination. These risks include:

- loss of *confidentiality* or inadvertent identification as an IDU
- inadvertent disclosure of HIV status
- negative reaction and consequences in response to publicised results
- arrest and incarceration.

Another special ethical consideration when conducting surveillance among IDUs is the person's ability to provide true *informed consent* when under the influence of drugs or acutely seeking or withdrawing from drugs.

Special Ethical Considerations, continued

In addition, extra concerns arise in studies that provide monetary incentives for participation. Obtaining cash for drugs may place inappropriate motivation on IDUs to participate.

Assuring confidentiality

Confidentiality protects subjects from the negative consequences that may arise from participating in a study or survey. Be aware of any of your country's laws that may complicate participation. These may include:

- laws prohibiting injecting drug use that have severe penalties
- more severe penalties for those identified as dealing drugs
- laws requiring reporting of people with HIV infection
- paraphernalia laws.

IDUs asked to participate in a survey or study should understand potential threats to their confidentiality. They should also understand the steps you will take to minimise the threats.

Ensure interviewer safety

Conducting HIV surveillance among IDUs requires face-to-face contact with drug-dependant people who may have criminal histories, psychiatric conditions, or violent tendencies, or all three. These persons may pose a risk to the interviewer's safety. Interviewers should be trained how to assess intoxication and how to ensure their own safety. Additionally, IDUs who are high or in withdrawal should not be interviewed.

Summary

Due to unsafe injecting practises and unsafe sex, IDUs are at high risk for getting and transmitting HIV and other blood-borne illnesses. In many countries with low-level and concentrated epidemics, HIV has spread most rapidly among IDUs.

Due to the illegal nature of intravenous drug use, locating and accessing this population can be difficult. Depending on how IDUs are organised and how easily they are accessed, different sampling approaches may be more or less feasible. As drug use is stigmatised and usually illegal, special ethical issues must be considered when conducting surveillance among IDUs.

NOTES

Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of this unit. Make any changes you want to make. We will discuss the questions and answers in a few minutes.

Small group discussion

Get into small groups to discuss these questions.

1. Does your country conduct behavioural or sero-surveillance or both among IDUs?

2. In your country, who are the *gatekeepers* of this population?

3. What is the legal context of injecting drug use in your country? If you don't know, how would you go about learning about the laws in your country?

4. In your country, what methods are used to sample IDUs?

5. In your country, what behavioural and biological measures have been used when conducting surveillance of IDUs?

6. In the past five years, has the prevalence of HIV among IDUs in your country increased, decreased, or remained about the same?

Apply what you have learned/ case study

Try this case study individually or in a group. We'll discuss the answers in class.

Behavioural surveillance among IDUs in Sadcity, Globa

Part 1: Collecting information to plan surveillance activities

You are the HIV surveillance officer for Sadcity, a medium-sized city in northern Globa and a major transit point on the drug-trafficking route between Globa and Boardland. There have been increasing reports of local injection drug use, particularly among youth in your area, that have alerted you to a potential for increased HIV transmission among this population.

Your city has asked you to work with the city's police authorities to undertake an HIV behavioural and biological surveillance survey of drug injectors in the city to design targeted HIV prevention interventions.

There are four detoxification centres in Sadcity. Two of the centres are government facilities that serve drug addicts who are court-ordered to attend detoxification, and the other two are private and voluntary. You decide to start by collecting information from the city's detoxification centres.

With the help of the detoxification centres' staff, you conduct voluntary HIV testing and return the results to the patients.

1. What are the advantages and limitations of this approach? (i.e., collecting information from the city's detox centres)

2. Describe the steps you take to conduct this survey. How do you ensure confidentiality?

3. What biological markers do you include? Why?

4. How might HIV prevalence estimated from IDUs in detoxification centres differ from that in IDUs outside of detoxification centres?

Part 2: Building key alliances with community networks involved with IDUs

Overall, HIV prevalence among injectors in the detoxification centres was 25.5%. HIV prevalence was significantly higher among people attending the government facilities compared to the private detoxification centres. Only 20 injectors were over the age of 25 years. None were female, although the police indicated that many of the city's SWs are also IDUs. No information was collected on needle-sharing or sexual behaviours.

Part 2: Building key alliances with community networks involved with IDUs, continued

You determine that information gathered from the detoxification centres is not sufficient to fully characterise all the injection drug use in the city. Your office decides to conduct a formative assessment to describe both the young injecting network and other networks and subpopulations of IDUs.

5. Who are the key stakeholders and community groups with whom it is necessary to build alliances?

6. How will the HIV team engage the different stakeholders?

Part 3: Choosing approaches to combined behavioural and biological surveillance

You form an HIV surveillance team meet to meet with key informants, including HIV prevention and care governmental and nongovernmental organisation personnel, STI clinic and detoxification centre employees, police in the area and former IDUs.

A brief meeting is organised, at which you, the HIV surveillance officer, inform the *stakeholders* about the need for and purpose of combined HIV behavioural and biological surveillance of IDUs in Sadcity. You also gather information from the stakeholders on the local population including any subgroups of IDUs.

Using information gathered from stakeholders, the HIV team characterises a wide range of IDUs. Three geographically distinct groups of IDUs are identified: 1) a group of young injectors who use heroin and congregate in the centre of Sadcity; 2) a group of older injectors who congregate on the outskirts of town; and 3) a group of injecting street-based female SWs who mainly congregate in Sadcity's slum communities. While the groups are geographically and socially distinct, you find that members of the three groups do interact to some extent.

With verbal assurance of the cooperation of the stakeholders, the HIV team is now ready to begin planning for the survey.

7. What sampling schemes would be appropriate for conducting community-based sampling of IDUs in Sadcity?

8. What are the advantages and disadvantages of using TLS versus RDS?

9. Given the limited information available at this point, which method do you think will work best in Sadcity?

Part 4: Implementing RDS

You decide that RDS is the most feasible method for sampling IDUs in Sadcity. You select a sample size of 600 and decide to start with six seeds. As you have limited financial and human resources, you must accomplish the survey in three months.

10. What types of characteristics of IDUs do you think would be important for seeds to have based on the information given by the stakeholders? Why?

11. How would you go about finding what kind of incentive would be most appropriate for this population? Other than cash, can you think of other types of incentives that IDUs might prefer?

12. Can you think of any ethical considerations of providing incentives?

13. What questions do you want to include in your survey?

You decide to use a total of six seeds, with two seeds in each IDU network (young injectors, older injectors, injecting SWs). The people you select as seeds appear well-connected in the IDU community. Although you could provide financial incentives, for ethical reasons you decide to give meal and clothing vouchers as recruitment incentives.

After three weeks, you determine that although the recruitment chains from the seeds you selected among the younger injectors and the injecting SWs have grown, the two seeds you selected among older injectors have not recruited anyone.

14. What are your options for reaching the older IDUs now?

You decide to find two new older IDU seeds. The recruitment chains from all seeds expand until you are one-third of the way to your calculated sample size and halfway through the time allotted.

You are nearing the end of the recruitment and you have passed your projected sample size.

15. How do you end recruitment? What problems might you encounter when trying to end recruitment?

Part 5: Analysis

Your team exceed your required sample size of 600 and successfully recruits 680 IDUs. It is now time to prepare a report on your findings.

16. What data analysis software do you use?

17. What information did you collect in order to analyse these data? Do you recall if you mentioned collecting these variables when planning the survey?

RDSAT is currently the most appropriate analysis software for analysing data collected using RDS methods. It is open source, available online at: http://www.respondentdrivensampling.org/main.htm

To analyse your data, it is necessary that you have data on each respondent's social network size and by whom each respondent was recruited.

Part 6: Epilogue

The RDS-adjusted population estimate for HIV was 27.1%. Sixty percent of IDUs were under the age of 25 years and a quarter were female. Of the respondents, 58.6% said they had used a needle previously used by someone else, and 63.0% said they gave a needle they had used to someone else in the last year. Many IDUs indicate that needles available at the pharmacies are too expensive.

Based on these findings, the public health commissioner directs the HIV programme manager to initiate the following interventions:

- Expand drug detoxification and treatment programmes in Sadcity.
- Establish a needle-exchange programme.

Unit 4

Men Who Have Sex with Men

Overview

What this unit is about

This unit describes the background and special considerations associated with studying men who have sex with men (MSM). It explains sampling and surveillance methods and recommends specific surveillance methods for this group. The unit ends with a case study about MSM and specific study issues.

Warm-up questions

1. True or false? Because MSM are homosexual, there is no risk that HIV will spread to the rest of the population, including women.

   True False

2. List two possible points of access where MSM can be found.

3. Given that MSM are often hard to reach because of discrimination and stigmatisation, two successful sampling methods in this group are _____ and _____.

4. What are some of the ethical issues to consider when conducting HIV surveillance of MSM?

5. What are some possible behavioural indicators to include when conducting HIV surveillance among MSM?

6. What are some possible biological measures to include when conducting HIV surveillance among MSM?

Introduction

What you will learn

By the end of this unit, you should be able to:

- describe the special considerations associated with surveillance in men who have sex with men (MSM)
- list organisations that possibly can assist in surveillance of MSM
- describe options for sampling and surveillance methods among MSM.

Background

Definitions

The term *men who have sex with men* (MSM) describes a type of behaviour, as opposed to a specific group of people. MSM include self-identified gay and bisexual men, as well as men who have male-male sex and self-identify as heterosexual.

Another group that historically has been included in MSM are individuals who are *transgendered*. "Transgender" is an umbrella term that generally refers to biological males who have undergone or are in the process of undergoing treatment to make them anatomically female. Keep in mind that some people self-identify as transgendered without having undergone any sort of surgery or treatment. In some cultures, particularly in Asia, there are also culturally endorsed roles for persons identifying as neither male nor female. These people are considered a third gender.

Many transgendered persons, because of their marginalisation from mainstream society, have few options for employment and are, consequently, employed in the sex industry and other service-oriented jobs.

In some countries, male-to-male sex happens within hidden gay communities. These communities are often served by health clinics and other institutions that cater to gay men and can be used as *sentinel sites*. Elsewhere, however, MSM do not identify as gay. In these locations, male-to-male sex is clandestine and there are no easily accessible clinics or other sentinel sites for communities of MSM.

Role of MSM in the HIV epidemic

MSM are one of the groups at highest risk for HIV infection in the Americas, Asia, Europe, and Oceania. There are, however, a few surveys that have looked at HIV infection among MSM in Africa and the Eastern Mediterranean region. Surveys in this group are especially difficult because of widespread denial and *stigmatisation* of homosexual

Role of MSM in the HIV epidemic, continued

behaviours. Improved awareness and implementation of *formative assessment* are needed before conducting formal HIV *surveillance* activities in this population.

MSM can be exclusively homosexual and have sex only with men. They also can be bisexual and have sex with both men and women. When developing the *sampling frame*, it is important to note that in many societies, MSM also may have sex with women.

In general, the risk of HIV transmission in anal sex between men is greater than the risk of transmission in vaginal sex between men and women. This fact is what puts MSM at higher risk in general. Men who have sex with both men and women may be an important *bridge* group between a sub-population at high risk for HIV infection (MSM) and the general population at lower risk for infection.

In some countries, *marriage pressure* (that is, family pressure on sons to marry to provide stability for parents and the continuation of the family name) may be greater than in others. Marriage pressure may be a factor that contributes to the higher rates of bisexual behaviour.

Prevalence of HIV among MSM

The data below illustrate the range of HIV prevalence among MSM in the world and includes HIV prevalence trend data for some locations. The rapid rise in prevalence in many of these locations is cause for concern and illustrates the need for *behavioural* and *serological surveillance* among MSM.

The availability of data on the prevalence of HIV among MSM varies by region and country, including the following examples:

- Various studies have indicated elevated *prevalence* rates among MSM in Kenya at 11% (voluntary counselling and testing [VCT] sites); Dakar, Senegal (22%); and in Khartoum, Sudan (9%) (Angala et al., 2006; Wade et al., 2005; Elrasheid, 2006, UNAIDS)
- A study in Trinidad and Tobago found HIV prevalence of 20% among MSM, 25% of whom said they regularly also had sex with women (Lee et al., 2006, UNAIDS)
- In the Russian Federation, HIV prevalence among MSM varies from place to place. In Nizhni Novgorod, 9% of MSM were HIV-positive in 2006 (Ladnaya, 2007), but lower HIV prevalence has been found in Yekaterinburg (4.6%), Saint Petersberg (3.8%), and Moscow (0.9%) (Smolskaya et al., 2004; Smolskaya, 2006, UNAIDS)

Prevalence of HIV among MSM, continued

- Two percent of the AIDS cases reported in Jordan between 1997 and 2005 were attributed to MSM sexual activity (UNAIDS)
- Results of a 2004 study in Karachi, Pakistan reported 4% of male *sex workers* (SWs) and 1.5% of hijras were HIV-positive. (Bokhari A et al. HIV risk in Karachi and Lahore, Pakistan: an emerging epidemic in injecting and commercial sex workers. International Journal of STD & AIDS 2007;18:486-492.)
- In Bolivia, HIV prevalence of 22% and 15% has been found among MSM in Santa Cruz and La Paz, respectively (Ministerio de Salud y Deportes, ONUSIDA, 2007ab, UNAIDS)
- The main mode of HIV transmission in Slovakia is through the sexual activity of MSM: 66% of the cumulative reported HIV cases have been among MSM. (www.euro.who.int/aids/ctryinfo/overview/20060118_39).

The following table illustrates the range of HIV prevalence among MSM in Asia and includes HIV prevalence trend data for some locations. The rapid rise in prevalence in many of these locations is cause for concern and illustrates the need for behavioural and serological surveillance among MSM.

Table 4.1. HIV prevalence among MSM in Asia.

Location	%	Sample*/Date
Dhaka, Bangladesh	0.4	Sentinel surveillance/2005
KathSadcity, Nepal	3.9	Sentinel surveillance/2005
Bangkok, Thailand	17.3 28.3	1121 TLS/2003 400 TLS/2005
Beijing, China	0.8 4.6	325 RDS/2004 427 RDS/2005
HCMC, Vietnam	6 8	208 CV/20002 600 Snowball/2004
Phnom Penh, Cambodia	14 **	206 TLS/2000 305 RDS/2005
Shenzhen, China	0.7 1.3	113 TLS/2002 267 TLS/2004

** CV = convenience sampling; RDS = respondent-driven sampling; TLS = time-location sampling.*

** Not available

Role of MSM in HIV surveillance

HIV surveillance of MSM is essential in all countries. Data throughout the developing world indicate increasing HIV prevalence among MSM populations. Routine surveillance among MSM, however, is sporadic or nonexistent, creating the potential for prevalence to rise even higher while going undetected.

The purposes of HIV surveillance in MSM are:

- to monitor disease occurrence and its antecedents
- to obtain data to use in planning and evaluating prevention and care programmes
- to advocate for prevention resources
- to improve the health, social welfare, and equal rights of MSM.

Table 4.2 summarises how HIV is affecting MSM throughout the world.

Table 4.2. HIV burden among MSM.

Region of the World	MSM HIV Burden
▪ North America ▪ Australia ▪ New Zealand ▪ Most Western European nations	MSM are the most affected population
▪ Asia ▪ Latin America	Depending on the country, MSM constitute a large proportion of persons affected by HIV
▪ Sub-Saharan Africa ▪ North Africa ▪ Middle East	Data on the burden of HIV among MSM are limited

Discussing the table

Looking at Table 4.2, answer the following question:

a. For what regions is data on the burden of HIV among MSM limited?

Bridges and overlap with other populations

All over the world, a proportion of MSM also have sex with women. The potential for MSM to bridge HIV infection to heterosexual women is an issue that requires monitoring and investigation. Surveys of MSM always should ask about all types and genders of partners MSM may have. MSM also can be members of other *high-risk populations* covered in this module. MSM are found among *injection drug users* (IDUs), patients of *sexually transmitted infection* (STI) clinics, street children, prisoners, and *sex workers* (SWs). Being a member of two or more high-risk groups increases the risk of HIV infection for MSM.

Conducting a Formative Assessment

Consider where to find MSM

To begin formative assessment and to aid in accessing MSM and to ensure proper use of surveillance data, *alliances* should be formed with organisations and individuals that are trusted by the MSM community. Additionally, if they exist, enlisting the support of current prevention programmes for MSM can help establish the infrastructure for the surveillance system.

Surveillance activities should enlist the assistance of:

- health authorities
- the Ministry of Interior
- social services
- MSM groups
- *gatekeepers*, such as gay activists
- organisations that represent MSM interests
- existing public health prevention programmes
- the police and other law enforcement personnel.

Surveillance officers should also enlist the support of people whom the MSM community trust as sources of information:

- natural leaders of the MSM community; asking around can usually elicit names of MSM leaders
- owners of MSM businesses and venues, such as saunas and bars
- employees of MSM businesses and venues, such as bars, dance clubs, hair salons
- influential members of the fashion industry
- dance club owners
- owners and operators of bathhouses.

Consider where to find MSM, continued

It is important to remember that alliances need to be viewed as mutually beneficial. You should exercise caution and not alienate community gatekeepers. Mapping the geography of the MSM community is an essential part of surveillance for this group, as for any other *hard-to-reach group*.

An important issue for preliminary investigation is to determine to what extent MSM can be found in venues that are identifiable and accessible to the investigators. In some areas there may be no such venues, with MSM only accessible through their personal social *networks*. These distinctions are ways to choosing the appropriate *sampling* method.

Conducting ethnographic mapping

Conduct *ethnographic mapping* to create a comprehensive description of:

- the social geography of MSM
- the places where MSM congregate
- time periods when MSM congregate.

This information is crucial for choosing a sampling method and for creating a sampling frame.

In terms of access in countries with gay communities, points of contact include:

- restaurants
- cafes
- beaches
- dance clubs
- gyms
- parks
- bathhouses
- social organisations
- beauty salons
- other *cruising areas.*

Cruising areas are public spaces, such as parks, bathhouses, and dance clubs, where MSM meet, congregate, and arrange or engage in sexual activity.

Other points of access

MSM venues in countries without well-developed gay communities will be more difficult to identify. Some MSM do not congregate in particular locations. They deliberately may be elusive due to stigmatisation of homosexual behaviour. Other points of access may be through gay websites or gay-focused services, Internet chat rooms, and clinics specialising in MSM health.

Including organisations that provide HIV prevention or AIDS care services to MSM as venues has the potential to inflate estimates of HIV infection or HIV risk behaviour or both and should not be done.

Selecting a Sampling Method

Although surveillance of MSM may be more difficult than surveillance of female SWs, the methods for approaching surveillance efforts are similar.

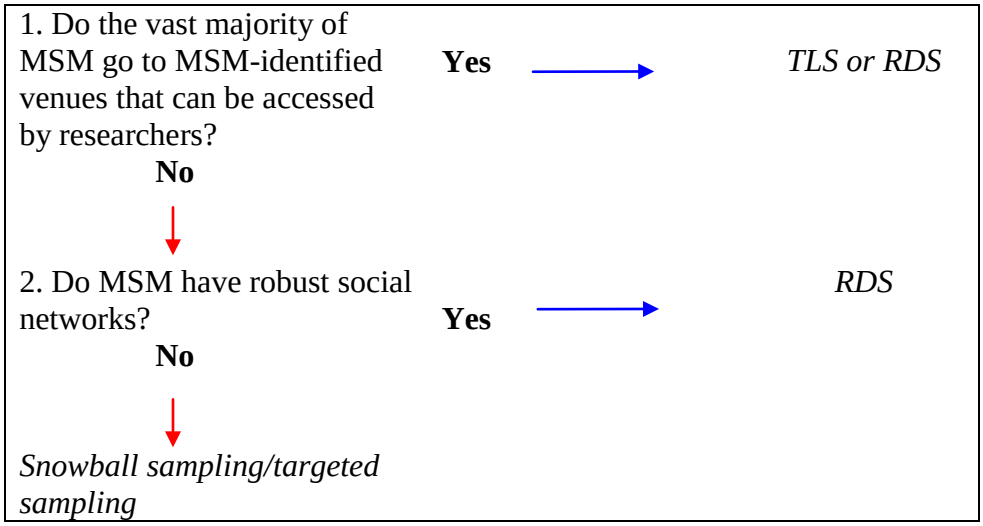
As with surveys of other hard-to-reach populations, getting a representative sample is difficult. There is no clear sampling frame and many studies have relied on various *non-probability sampling* methods. Because these samples are not representative, it is difficult to use them to compare *indicators* over time. Two methods that have been used successfully to monitor HIV prevalence and *risk behaviours* in MSM are:

- *time-location sampling* (TLS)
- *respondent-driven sampling* (RDS)

In some circumstances, neither TLS nor RDS will be appropriate for MSM in your area. In this case, using traditional *snowball sampling* or mixed methods may be the only appropriate option. Figure 4.1, on the next page, will help you select an appropriate sampling method for MSM in your area.

Selecting a Sampling Method, continued

Figure 4.1. Appropriate sampling methods for MSM.



Discussing the figure

Looking at Figure 4.1, answer the following questions:

a. If MSM do not congregate in identifiable venues and do not have robust social networks, which sampling methods may be most appropriate?

b. Is this sampling methods a *probability sampling* or non-probability sampling method?

Male sex workers

Male sex workers (MSWs) are a highly mobile and often invisible sub-population of MSM. MSWs are men who sell sex to women as well as men who sell sex to men.

Male sex workers have been found worldwide. In Morocco, Peru, and Turkey, MSWs are known as *gigolos* (hustlers) who usually self-identify as being heterosexual and tend to have foreign, often European, male and female clients. In Morocco, *prostitués homosexuels* (homosexual prostitutes) usually self-identify as homosexual or gay, and in Argentina they may be referred to as taxi boys. In Indonesia and India, waria and hijra, respectively, are transgendered SWs.

In areas where MSM sell sex to other men, sampling techniques used for SWs may be appropriate and effective. Your formative assessment will help you decide which sampling approaches are appropriate and feasible for sampling MSWs. Please refer to Unit 2 (Sex Workers) for further information on the methods of sampling SWs.

Measures and Indicators

Comprehensive HIV surveillance among MSM includes surveillance of:

- HIV infection
- STI infection
- risk behaviour(s)
- partner characteristics.

The ideal surveillance system also should measure specific healthcare outcomes and societal attitudes and practises. Moreover, surveillance should describe the diversity of male-to-male sexual practises, their potential for HIV transmission, and their potential for bridging to other populations.

Biological measures

Measuring HIV sero-prevalence among MSM is an essential component of surveillance. The high-risk sexual behaviour among MSM also makes STI testing a useful indicator for surveillance. For a description of the available STI and HIV tests, refer to the WHO test kit evaluation programme (http://www.who.int/diagnostics_laboratory/evaluations/en/).

The biological measures to include in surveys of MSM are similar to those for female SWs:

- *syphilis*
- *gonorrhoea* (urethral, rectal, and pharyngeal)
- *Chlamydia* (urethral, rectal, and pharyngeal)
- *herpes simplex virus type-2* (HSV-2)
- syndromic proctitis (inflammation of the anus).

In areas where there may be suspected overlap between MSM and IDUs, *hepatitis C virus* (HCV) may also be a useful biological marker. Tests for HCV, however, may be expensive.

Behavioural measures

Measuring changes in sexual behaviour among MSM helps explain trends in sero-prevalence data on HIV and STIs.

Behavioural surveillance among MSM attempts to determine:

- the frequency of *unprotected sex*
- the characteristics of partners of MSM
- the frequency of injection drug use.

When conducting behavioural surveillance among MSM, core *UNGASS* indicators include:

- percentage of MSM who received HIV testing in the last 12 months and who know the results
- percentage of MSM reached by prevention programmes
- percentage of MSM who correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV transmission
- percentage of men reporting the use of a condom the last time they had anal sex with a male partner
- percentage of MSWs reporting the use of a condom with their most recent client.

Behavioural measures, continued

Behavioural surveillance of MSM may collect information on:

- condom use
- number of partners
- type of partners
- frequency of unprotected insertive anal intercourse (UAI)
- frequency of unprotected receptive anal intercourse (URAI)
- STI treatment-seeking
- migration patterns
- marital status
- history of sex work
- HIV test-seeking and result-seeking
- history of imprisonment
- injecting drug use
- contact with SWs
- MSM venues.

Reference to indicators

Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found in Unit 1.

Indicators recommended by international bodies will not necessarily capture all behaviours relevant to your area. Some questions will be for local use only (for example, exposure to specific prevention programmes or assessing particular risky practises). The formative assessment phase should be used to determine the local questions of greatest relevance to the epidemic in your area.

Special Ethical Considerations

Due to the covert nature of life for many MSM in many developing countries, MSM are a *vulnerable population*. Their participation in surveillance activities may place them at risk for harm and discrimination. These risks include:

- loss of *confidentiality* or accidental identification as an MSM
- inadvertent disclosure of HIV status
- negative reaction and consequences if results are made known
- physical abuse
- imprisonment
- rejection by family members.

Certain considerations must be taken into account when attempting surveillance in these populations, including:

1. the stigma associated with being an MSM, which prevents many from being open about their sexual orientation
2. the illegal status of male-to-male sex in the region, which results in police harassment and discrimination by the general population.

Language, social perspectives, and taboos surrounding homosexual activity exist in many countries. These can affect the completeness of surveillance systems and the quality of the data.

Assuring confidentiality

Confidentiality protects subjects from the negative consequences that may arise from participating in a study or survey. Be aware of any of your country's laws that may complicate participation. These may include:

- laws prohibiting homosexual activity
- laws prohibiting injection drug use
- laws requiring reporting of individuals who have HIV infection.

Assuring confidentiality, continued

People asked to participate in a survey or study should understand potential threats to their confidentiality. They should also understand the steps that investigators will take to minimise the threats. Explaining these issues to potential subjects is part of the *informed consent* process. Steps you can take to minimise threats to confidentiality may include:

- conducting surveillance among MSM anonymously
- conducting interviews with MSM in private settings
- allowing only authorized personnel access to any identifying information
- keeping study documents in a locked, limited-access room
- having all staff sign confidentiality forms and undergo training in research ethics
- using codes in lieu of participants' names
- informing potential survey participants during the informed consent process of the actions you will take to minimise threats to confidentiality.

Summary

MSM include self-identified gay and bisexual men, men who have engaged in male-male sex but who self-identify as heterosexual, and transgendered people. MSM are at high risk of acquiring HIV and other STIs due to their high-risk sexual behaviours. MSM make up a substantial proportion of the HIV burden. Behavioural and HIV sero-surveillance of MSM is particularly important in countries and regions where little is known about MSM. Respondent-driven sampling (RDS) and time-location sampling (TLS) are well-suited for sampling MSM who have either identifiable venues or robust social networks. As MSM often are stigmatised and as their behaviour may be criminalised, you must consider and address the special ethical issues of conducting surveillance among this group.

Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of this unit. Make any changes you want to make. We will discuss the questions and answers in a few minutes.

Small group discussion

Get into small groups to discuss these questions:

1. Does your country conduct behavioural and/or sero-surveillance of MSM?

2. In your country, who are the gatekeepers of this population?

3. In your country, what methods have been used to sample MSM?

4. In your country, what behavioural and biological measures have been used when conducting surveillance of MSM?

5. In the past five years, has the prevalence of HIV among MSM increased, decreased, or remained about the same?

Apply what you have learned/ case study (1)

Try this case study individually or in a group. We'll discuss the answers in class.

Biological and sero-surveillance of MSM in Great Gorge, Globa

Part 1: Collecting information to plan surveillance activities

Great Gorge is a coastal, cosmopolitan city in southern Globa with a population of three million.

Because Great Gorge is the financial and cultural centre of the country, many men are drawn to the city. Homosexuality, however, is officially prohibited and the MSM population is hidden to avoid fines, physical abuse, imprisonment, deportation, or death.

Annual *sentinel surveillance* from the past three years has found an increase in the *incidence* of rectal gonorrhoea and proctitis among males who attend STI clinics in Great Gorge. The Ministry of Health is concerned that there may be an undetected epidemic of STIs and HIV among MSM.

Because homosexuality is illegal in Great Gorge, MSM are often discriminated against and harassed by local police, resulting in mistrust among MSM of local officials. In the past, therefore, the Ministry of Health has had difficulty conducting biological and behavioural surveillance among MSM.

Nevertheless, due to substantial evidence, the Ministry of Health has decided to conduct biological and behavioural HIV/STI surveillance among MSM this year. As the HIV surveillance officer of Great Gorge, you are tasked with designing and conducting this activity.

1. What information is required for planning the survey?

2. What research activity would your office use to obtain this information?

Part 2: Building essential alliances with community networks involving MSM

To plan for the survey, you must begin to understand the range of MSM sub-populations, the local vocabulary used to describe the MSM sub-populations, the venues where MSM congregate, and ways to identify gatekeepers. As you do not know how many MSM live in Great Gorge or where they congregate, you decide to conduct research to determine where and when MSM congregate and in what numbers, as well as other patterns of MSM activity. Information can be obtained from websites; through interviews with club and bathhouse owners and people in the fashion industry; through ethnographic mapping; and by observation.

3. How would you gain the trust of members of the MSM community?

Part 3: Mapping the MSM network and choosing a sampling approach

Enlisting the support of popular MSM in Great Gorge, you form a partnership with the local underground *non-governmental organization* (NGO) working with the MSM community and establish a working group or a *community advisory board* (CAB) to help gain access to other MSM. You can gain the trust of members of the community by letting them know that data are used for advocacy and for designing and delivering education and outreach. You also can work with local law enforcement agencies to ensure that police do not harass MSM who participate.

Through formative research, you find that a local MSM scene does exist. After conducting *focus group* discussions and in-depth interviews with MSM, you find out that MSM in Great Gorge do not often congregate in visible and accessible locations and that there are few specific locations where MSM can be found in large numbers. Although the community is hidden, there is a large network and solidarity exists within it. Most MSM find each other through websites, friends, night clubs, saunas, salons, and beaches. Sex takes place in some of these areas. There are also a range of MSM sub-populations, including MSWs, transgendered people, and married men with bisexual tendencies.

4. What sampling scheme is most appropriate?

5. What are the advantages and disadvantages of RDS?

Part 4: Collecting biological and behavioural data

You decide to conduct HIV prevalence and risk behaviour surveys of MSM every other year, using the RDS method. There are advantages and disadvantages to RDS. The method still is in the early stages of development; however, it has been shown to reduce in-group affiliation, where initial study participants tend to list people of similar demographics, such as socio-economic status levels, education, and interests. RDS also improves random probability of selection and the cooperation of surveillance participants because it uses a peer-referral method and a dual *incentive* structure.

6. What biological variables do you include?

7. What behavioural variables do you include?

8. What additional steps are needed to test for HIV?

9. What are some of the special ethical considerations for this surveillance activity?

Part 5: Preparing for the surveillance activity

To prepare for the surveillance activity, you hold a few focus group discussions with MSM and your CAB group to discuss a location in the city to conduct the survey, a common language used to identify sexual behaviours, the design of the coupon, and the types of incentives to offer. From this preparation, you are also able to come up with six *seeds* and surveillance staff for the sites, including nurses, counsellors, interviewers, and greeters.

10. What sub-populations did you include in selecting seeds?

11. What characteristics would you look for in selecting a site to conduct your surveillance activity?

Part 6: Analysing and disseminating data

You decide to assess the prevalence of HIV, syphilis, gonorrhoea, Chlamydia, and HSV-2, the types and number of partners, and the frequency of unprotected anal sex and vaginal sex.

You need a site that is easy to find, affordable to get to, and private. There should be enough space to store all the surveillance materials, and it should be clean and comfortable for the participants.

To get the behavioural and biological data, you need to obtain voluntary informed consent from MSM who agree to participate in the study. Ethical issues you should consider include maintaining participants' confidentiality and ensuring that interviewers are sensitive to issues facing MSM. Additionally, as you will be testing for HIV, you should have a way for persons who test positive for HIV to be referred to counselling and treatment.

This study produces the following results:

- HIV prevalence was 5%.
- Syphilis (TPHA) prevalence was 12%.
- HSV-2 prevalence was 16%.
- Gonorrhoea prevalence was 5%.
- Chlamydia prevalence was 6%.
- Eighty-five percent of MSM report unprotected anal sex with male partners.
- Some MSM engage exclusively in homosexual activity, while others consider themselves to be heterosexual and are married.

12. Describe how you would use the data collected to develop MSM-focused prevention programmes?

Part 7: Epilogue

Great Gorge has a large population of MSM, including MSWs, MSM who identify as homosexual, and men who are married and identify as heterosexual or lead covert lives. Because homosexuality is prohibited in the region, there is a lack of services for MSM and they can be fearful of the authorities. Due to the stigma associated with being MSM, they often do not seek medical care when it is needed.

The findings suggest MSM in Great Gorge are at high risk of acquiring and transmitting HIV. Some MSM have high rates of partner turnover and low rates of condom use; many do not seek treatment for STIs or other health problems; many are IDUs, and many have been incarcerated and beaten. Targeted interventions are needed to reduce stigma and promote safer sex practises among MSM in Great Gorge.

Based on these findings, the Ministry of Health directs the HIV programme manager to initiate the following interventions:

13. Engage peer and NGO outreach workers, as well as STI clinic staff, to educate MSM about the need for consistent condom use with non-regular and regular partners.

14. Distribute condoms to MSM through peers, workers at NGOs and STI clinics, night clubs, saunas, and salons.

15. Establish education and outreach programmes to encourage MSM to seek treatment for STIs.

Unit 5

Mobile Populations

Overview

What this unit is about

This unit describes the background and special considerations associated with conducting HIV/STI and behavioural surveillance among mobile populations. It explains sampling and surveillance methods and recommends specific surveillance methods for this group.

Warm-up questions

1. Which of the following terms is used to describe migrant labourers, fishermen, and truck drivers?

   a. involuntary migrants
   b. voluntary migrants
   c. military personnel
   d. none of the above

2. Which of the following terms is used to describe refugees and internally displaced people?

   a. involuntary migrants
   b. voluntary migrants
   c. military personnel
   d. none of the above

3. Of the following, which is *not* a reason why migrants are especially vulnerable to HIV?

   a. Female migrants may sell "survival sex" when they have no other source of income.
   b. Migrants usually have only one sexual partner.
   c. Migrants have limited access to healthcare.
   d. Migrants often live in settings where they are more likely to adopt risk behaviours.

4. Mobile persons often serve as a _____ between female sex workers and the general population. Additionally, due to migration patterns, mobile populations may bring HIV from high-prevalence areas to low-prevalence areas.

Warm-up questions, continued

5. List two possible locations where mobile persons may be found in large numbers.

   a.
   b.

6. What are some of the ethical issues to consider when conducting HIV surveillance among refugees or internally displaced persons?

Introduction

What you will learn

By the end of this unit, you should be able to:

1. distinguish between the various types of mobile populations
2. describe options for sampling and surveillance methods among mobile populations
3. describe the special considerations associated with surveillance in mobile populations.

Background

Definitions

This unit focuses on the special issues involved with conducting *behavioural surveillance* and HIV *sero-surveillance* in *mobile populations*. "Mobile populations" is the term used to refer collectively to groups of people who move from one place to another. They may move temporarily, seasonally, or permanently, and for either voluntary or involuntary reasons. *Migration* is one of many social factors that have contributed to the HIV epidemic. Migration refers to people moving from one area to another and does not imply permanent resettlement. Many migrant groups with increased risk of HIV are temporary migrants and may move for only a few weeks at a time.

Migration can be divided into two broad categories:

- *voluntary* and job-related migration, which is seen in truckers, skilled and unskilled labourers, and fishermen
- *involuntary* migration, which is seen in *refugees* and *internally displaced persons (IDPs)*.

The International Organization for Migration (IOM) is the leading inter-governmental organization in the field of migration and works closely with governmental, intergovernmental and non-governmental partners. The IOM has extensive information on various migrant populations and can be accessed here:
http://www.iom.int/

Voluntary migration

Although there are many different types of migration, a common mode of migration is *circular* or *oscillating migration*. This type of migration is characterised by young men and women leaving their rural communities to work in urban areas or construction sites. They return home periodically, depending on the distances involved. Over the past century, migration has

become common among rural men seeking employment in urban centres. Today, young women commonly migrate from rural areas to seek employment as domestic helpers or factory workers in urban centres.

Some examples of migration include the following:

- married and unmarried men who relocate from rural to urban areas for seasonal or long-term jobs and who may move with or without their families
- young, single men and women who migrate from rural to urban areas for industrial jobs, often living in dormitories or other group housing
- single and married women who travel weekly or monthly from rural to urban areas to work as domestic helpers.

In addition to including persons moving from their homes to work, the term “migrants” also includes people in the transportation industry, such as truck drivers and merchant seamen, who travel frequently across long distances.

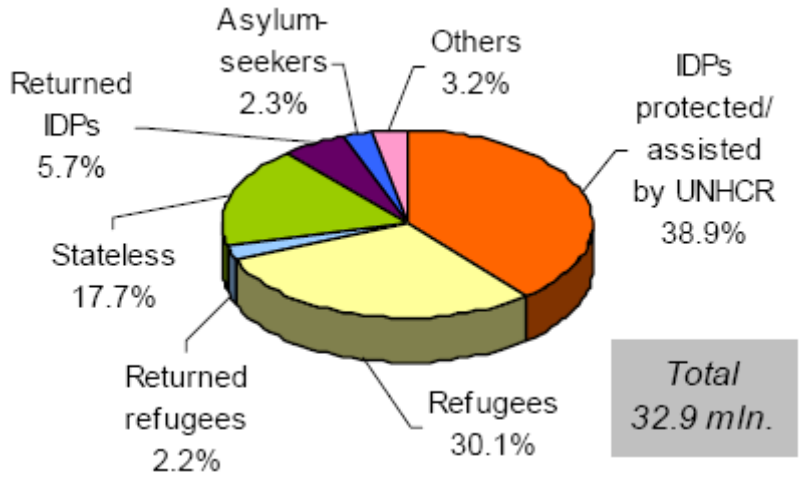
These mobile populations include many groups, such as the following:

- people who travel between home and business locations daily or weekly and who are away from home and family for short durations; for example, salesmen and short-distance truckers
- long-distance transportation workers who are away from home for several months, but who do not necessarily establish permanent residences
- merchant seamen.

Involuntary migration

Civil unrest is a major reason for involuntary migration. There are many people who are involuntary migrants, including refugees and IDPs. By legal definition, refugees are people who are outside their country of nationality and who are unable or unwilling to return to that country due to a well-founded fear of persecution because of race, religion, political opinion, or membership in a social group (Figure 5.1).

Figure 5.1. The global refugee population by category, end of 2006.



Source: *United Nations High Commission on Refugees* (UNHCR), accessed from http://www.unhcr.org/cgi-bin/texis/vtx/home/opendoc.pdf?id=478ce0532&tbl=STATISTICS

The term "refugee" applies only to people who have been displaced from their homeland and who have sought refuge in a second country. Internally displaced persons are people who have left their homes due to civil unrest, natural disasters, or political and/or religious persecution, but have not crossed an internationally recognised state border. IDPs are vulnerable to HIV because they are mobile; they often lack health services, protection, and food; and they may increase their involvement in transactional sex and population-mixing.[1]

[1] Mock N, et al. Conflict and HIV: A framework for risk assessment to prevent HIV in conflict affected settings in Africa. Emerging Themes in Epidemiology. Vol.1. Nov. 2004.

Involuntary migration, continued

The number of IDPs as estimated by the Internal Displacement Monitoring Centre as of Dec. 2007 is 26 000 000 in various countries worldwide (IDMC, www.internal-displacement.org), including the following United Nations figures:

- Afghanistan: 132 246 (UNHCR, September 2006)
- Sudan: 4 465 000 (OCHA, September 2007)
- Bosnia and Herzegovina: 131 600 (UN, October 2007)
- Russian Federation: 136 550 (UNHCR, January 2008)
- Democratic Republic of Congo: 1 312 368 (OCHA, December 2007)
- Kenya: 250 000 (UNOCHA, January 2008)
- Nepal: 50 000-70 000 (OCHA, July 2007)
- Yemen: 25 000-27 000 (UNHCR/EFP, October 2007)
- Philippines: 300 000 (WFP, January 2008).

Role of involuntary migrants in the epidemic

Studies have suggested that the longer-term ramifications of war and civil unrest are increased risk of transmission of HIV and other *sexually transmitted infections* (STIs) in refugee and internally displaced populations. There have been, however, only a few published studies of the *prevalence* of HIV and other STIs in these populations. Prevalence information is crucial for the development and implementation of effective programmes that address the needs of displaced populations.

In factors associated with transmission, complex emergency settings may differ substantially from more stable environments in which HIV research and prevention programmes have traditionally taken place. Risk factors for HIV and STIs differ between contexts, but in emergencies can include:

- massive population displacement
- disruption of family and social structures and ways of life
- disruption of sexual *networks*
- sexual interaction between military or paramilitary personnel and people affected by the emergency
- economic vulnerability of women and unaccompanied minors
- increased frequency of commercial sex work
- increased frequency of sexual violence, coercive sex, and rape
- psychological trauma
- disruption of preventive and curative health services
- unsafe blood transfusion practises at a time of increased need for blood transfusions due to trauma
- increased use of illicit drugs, often due to psychological trauma.

Role of involuntary migrants in the epidemic, continued

It is best to think about HIV and STI surveillance within the larger context of the medical, social, economic, and political needs of refugee and internally displaced populations. HIV and STIs seldom will be considered the highest priority item on the list of the myriad problems facing refugees and those who serve them. Nonetheless, these people are particularly vulnerable to HIV and have real needs for HIV prevention. To be successful, HIV surveillance needs to be closely co-ordinated with and through on-site medical and social relief programmes. It can then be integrated into the broader context of information-gathering about the refugees and their situation.

The risk of sexual transmission of HIV between local peoples and refugees and internally displaced populations depends on the following factors:

- the relative HIV prevalence in the two populations and the extent to which the two groups interact
- the prevalence of STIs in the vicinity
- whether displaced populations are housed in camps or are integrated into the community, which means more opportunity for sexual interaction.

Role of voluntary migrants in the epidemic

Mobile populations are at high risk for both acquiring and transmitting HIV and STIs.

Involuntary migrants are especially vulnerable to HIV infection for a number of reasons, including the following:

- Many migrant workers travel to, reside in, and work at locations with higher rates of risky HIV behaviour, including multiple sex partners and drug use.
- Female migrants may sell *survival sex* when they arrive at a new location and have no other sources of income.
- Migrants have limited access to health services, including HIV services.
- Several studies have demonstrated the importance of major drug transportation corridors in the spread of HIV.

In some countries, sex work may be common in border towns and port areas, where truckers or uniformed personnel travel. This sex work is often based in bars, cafés, or nightclubs. In some settings, *sex workers* (SWs) may have sex with drivers in their trucks as they wait in lines to

Role of voluntary migrants in the epidemic, continued

load or unload cargo or get proper documentation. SWs in some countries also are highly mobile.

Sex is not the only common way HIV is transmitted among migrants. Both male and female migrants are often at risk for *parenteral transmission* because of injection drug use, traditional medical practises, and unsafe therapeutic injections. The trafficking of illegal drugs is also an important driver of the epidemic among migrants.

An example

Although non-injection use of opium is a traditional practise in Afghanistan, injecting likely is a new behaviour. As reported in a 2003 UNODC study, 50% of injectors surveyed in Kabul, Afghanistan reported that they started injecting heroin while seeking asylum in Pakistan or Iran.

Bridges and overlap with other populations

Mobile people often serve as a *bridge* between female SWs and the general population. Additionally, due to migration patterns, mobile populations often bring HIV from high-prevalence areas to low-prevalence areas. The role of migration in the spread of HIV has been described primarily as a result of men becoming infected while they are away from home, often by contact with infected SWs, and infecting their wives or regular partners when they return.

Prevalence of HIV among mobile populations

The prevalence of HIV infection among mobile populations varies by country and region. Consider the following examples:

- HIV prevalence of 9% was reported among male and female independent miners in Lunda Norte province of Angola, which borders the Congo (Ministerio de Saude & CDC USA, 2006, UNAIDS).
- In Mali, 6% of travelling saleswomen were HIV-positive, as were 2.5% of truck drivers who took part in a survey (Ministere de la Sante du Mali, 2006, UNAIDS).
- It is estimated that thousands of Albanian women and girls have been working as SWs outside the country (e.g. in Western Europe or other Balkan countries) over the past 10 years. Most of them are young (20–24 years old) and have not received any sex education. During the last decade there also has been a dramatic increase in the mobility of the

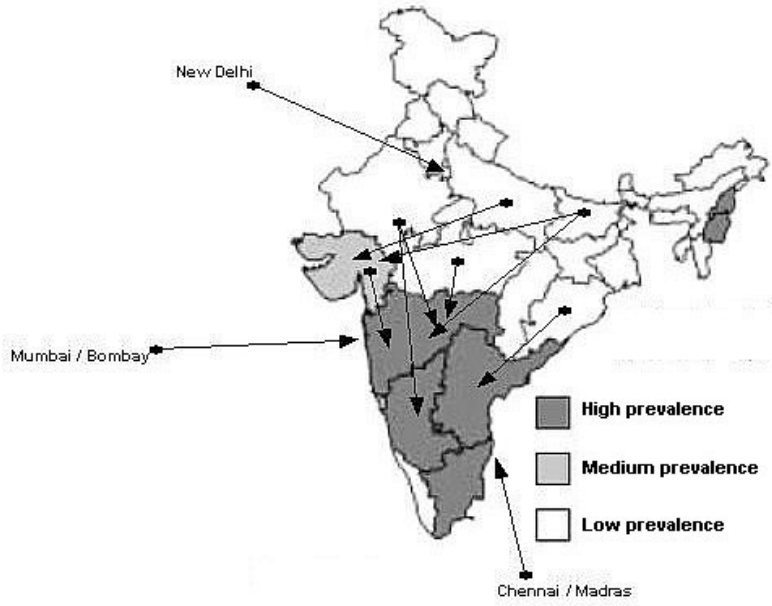
Prevalence of HIV among mobile populations, continued

Albanian population. According to estimates by the National Statistical Institute of Albania, the number of migrants is approximately 600 000 people, or about 18% of the population, the largest group being men aged 20–30 years (www.euro.who.int/aids/ctryinfo/overview/2006127_1).

- Between 600 000 and 1.3 million Nepalese men migrate to India for work. HIV prevalence of 8% has been found among labour migrants returning from Mumbai, India in the early 2000s (New Era & Family FHI, 2006), but lower levels (3% or less) have been found in more recent studies in Achham and Kailali, India (New Era & FHI, 2006). It is estimated that nearly half of all people living with HIV in Nepal have worked as labour migrants (WHO, UNICEF & UNAIDS, 2006).
- Miners working in the interior of Guyana reported HIV prevalence of 2.9% (Palmer et al., 2002, UNAIDS).
- Low HIV sero-prevalence (0.021%) among migrants coming into Kuwait for work between 1997 and 2006 was reported in a spectral analysis study. (Achtar S and Mohammad H. Spectral analysis of HIV seropositivity among migrant workers entering Kuwait. BMC Infectious Diseases 2008, 8:37).
- HIV prevalence as high as 4.4% has been found among some formerly displaced adults in Yei in southern Sudan, along the Ugandan border. (2006 AIDS Epidemic Update, WHO)
- One research study suggests that migrants are becoming infected in California and bringing the virus back to rural communities in Mexico at high rates. The researchers compared the prevalence of HIV in 800 Mexican migrants temporarily living in California (0.6%) to 1500 who migrated and then returned home to Mexico (1.1%). (www.sciencemag.org SCIENCE VOL 313 28 JULY 2006).

Figure 5.2, on the next page, shows migration from areas of low prevalence to states where prevalence is high. In many of the northern states, HIV prevalence among high-risk groups is less than 5%. Numerous migrants from those states moved to areas where HIV prevalence in antenatal clinics is above 1%, constituting a *generalised epidemic*.

Figure 5.2. Indian population movement from HIV low- to high-prevalence regions.



Source: National AIDS Control Organization (NACO), Government of India (2003).

Role of mobile populations in HIV surveillance

Worldwide there is a large and increasing number of migrant workers moving from rural villages to cities, as well as to other countries. Many countries, however, do not have a surveillance system to capture the magnitude of this migration, the flow pattern, or the profile of who is migrating. Existing HIV surveillance does not capture people's home communities and the key sites where they aggregate in host communities. Thus, there is a gap in our knowledge about the prevalence of and trends in HIV among the mobile populations. Unfortunately, this gap gives the impression that some countries that have large migrant communities with high HIV prevalence actually are low-prevalence countries.

Conducting a Formative Assessment

Consider where to find mobile populations

Conducting surveillance in mobile populations requires gaining access to the full range of sub-populations in the area. Due to the diversity of these sub-populations, locating all areas where mobile persons can be found and gaining access to them is challenging. You can locate and access mobile persons by:

- visiting the locations and venues where they congregate or work
- interviewing and working with people who have regular contact with mobile persons
- collaborating with organisations that provide services to these groups.

HIV prevalence may be highest in well-travelled border towns, ports, and areas where refugees and IDPs seek refuge. These sites therefore may be appropriate and convenient for surveillance. Possible locations where mobile persons may be found in large numbers include:

- truck stops and roadside hotels
- neighbourhoods known as refugee areas, such as particular slum communities
- refugees settings
- health clinics that serve refugees or IDPs.

Consider where to find mobile populations, continued

Before deciding on a sampling method you should decide whether to sample at the point of origin or the point of destination for migrants and mobile populations. This decision will depend on the aggregation of people at one end or the other, as well as whether the effect of the epidemic is being assessed for the geographic region that is the point of origin or the point of destination.

The UNHCR provides information on assessing, monitoring, evaluating, planning, and lessons learned regarding HIV/AIDS and refugee programmes in the field as information on behavioural surveillance studies and workshops related to HIV/AIDS among refugees and internally displaced persons. Further information is available at: **http://www.unhcr.org/protect/459e13fc2.html**

The *Family Health International* (FHI) report "Protecting People on the Move: Applying Lessons Learned in Asia to Improve HIV/AIDS Interventions for Mobile People" further discusses how to identify sites that fuel the spread of HIV or create conditions that make mobile people vulnerable to HIV. This report is available online at: **http://www.fhi.org/en/HIVAIDS/country/Asia/res_PeopleonMove2006.htm**.

The Fafo Institutes for Labour and Social Research and Applied International Studies have developed methods of accessing hidden populations, such as exploited migrants and trafficked persons. Further information is available online at **http://www.fafo.no/indexenglish.htm**

Forming alliances

The next steps will involve forming and maintaining *alliances* with the organisations and individuals that are trusted by the segment of the migrant community in which you are interested, such as:

- the UNHCR
- border patrol, immigration police, customs agents, and harbour masters
- employers
- employment agencies
- cafe owners
- union officials
- operators of truck stops, fish markets, or other places where these groups may congregate
- *non-governmental organizations* (NGOs), such as the Red Crescent Society
- local community leaders; for example, the town mayor and the department of transportation.

Forming alliances is an ongoing process that must be developed over time and will help in each stage of preparing for surveillance. When planning and implementing surveillance activities, it is important to understand the power structures that influence the movement and behaviour of mobile populations. It will also be helpful to enlist the support of any currently existing intervention programmes for migrant workers and populations. This will be extremely helpful in setting up the infrastructure for the surveillance system and disseminating results of the surveillance activity.

Obtaining community approval

Community approval promotes trust and confidence among community members who will be involved. It also reflects respect for local community customs. Given this, it is recommended that *second-generation surveillance* involve regular consultation from the community. *Community advisory boards* (CABs), made up of various leaders, can provide consultation, input, and advice on the design and implementation of surveillance. Below is a list of potential members for a CAB for HIV surveillance among migrant workers at a large manufacturing plant. The actual composition of a CAB will depend on the characteristics of the community and the nature of the surveillance activity, but it may include some of the following:

- union leaders
- employers
- employee occupational health centre workers
- employees elected by co-workers at large
- designated employee safety officers
- factory floor managers
- factory owners
- community leaders
- Ministry of Labour
- Ministry of Interior
- NGOs and community-based organisations
- other relevant partners identified through formative assessment.

Identifying the migrant populations that are of greatest interest to you and the best ways to approach these groups is an important first step, and the core of your *formative assessment*. Figure 5.3, on the next page, lists some examples of what migrant groups might be useful for particular communities and how to access the populations.

Select a Sampling Method

Sampling methods

Methods for surveillance in migrants are similar to those used in other high-risk populations in this module:

- HIV prevalence studies
- surveillance for STIs
- behavioural surveys to identify social, behavioural, and biomedical risk factors associated with HIV transmission.

Figure 5.3. Sampling methods for mobile populations or displaced persons.

1. Is there a complete list of mobile persons, such as a register of all refugees at a particular refugee camp?	**Yes** →	*Simple random sample, consecutive sample*
No ↓		
2. Do mobile persons congregate in identifiable and accessible locations in high proportions, such as in specific residential areas?	**No** →	*Respondent-driven sampling (RDS) or snowball sampling**
↓ **Yes**		
3. Is creating a list of mobile persons associated with each site feasible (such as all foreign day-labourers waiting for employment at a particular location)?	**No** →	*RDS*
↓ **Yes**		
4. Are a high proportion of mobile persons likely to be accessible at data collection sites on randomly chosen days/times?	**No** →	*RDS*
↓ **Yes**		
Time-limited sampling (TLS)		

*Note: Persons targets for your sample must be highly networked for you to use RDS. If they are not highly networked, snowball sampling or another *non-probability sampling* technique may be the most appropriate. Your formative assessment will help you determine whether the community is networked enough for RDS.

Sampling methods, continued

There is no one "best" sampling method for use in all situations. In some situations, when neither TLS nor RDS is appropriate, a facility-based sampling method may be the most viable option. The best way to sample these groups will depend on which specific groups of workers you wish to survey and the best places to find them (Table 5.1).

Table 5.1. Possible methods of surveying various mobile populations.

Mobile population	Possible survey methods
Truck drivers and their assistants	▪ simple random sampling, *cluster sampling* or *systematic sampling*, if trucking companies provide lists of their employees
Miners, factory workers, and construction workers	▪ during regular occupational health check-ups ▪ if housed by a company, lists or maps can be used for simple random sampling or multi-stage cluster sampling
Self-employed mobile persons, such as truck drivers and fishermen	▪ TLS, used, for example, among truck drivers stopping for dinner along a specific highway
Merchant sailors	▪ simple random sampling; for example, if a list of seamen exists at a union hall
Refugees and IDPs, in closed camps	▪ household-based surveys within refugee camps ▪ systematic survey of refugees as they enter the camp or from the camp registry
Refugees and IDPs, in community settings	▪ household-based surveys ▪ TLS of day labourers in areas where they congregate

An example, sampling migrant workers

An important element of these studies relates to the sexual networks and sexual behaviours of migrant workers. Also, much of the surveillance needs to be based at the workplace, not just in neighbourhoods where workers live. Migrant workers often are introduced to new patterns and norms of sexual behaviour through colleagues in the workplace.

Thus, to provide a good *sampling frame* for migrant populations, the following steps are suggested:

- List all working sites of migrants, by geography or time location; for example, all large industrial facilities with dormitories for migrant workers or all highway stops that cater to long-distance truck drivers.
- Based on HIV prevalence or the potential for instituting prevention programmes, choose the type of site of interest to you. Select sites for surveillance from the list you generate. If the number of people working at the sites is small (for example, on fishing boats or driving trucks), you may need to include the entire target population in the sample. If there are multiple large sites, you can pick one or two randomly, depending on sample size calculations.
- At selected sampling sites, take all or select systematically some respondents for interview.

Measures and Indicators

Both behavioural and biological measures of HIV, STI and *risk behaviours* can be collected in a variety of ways. The frequency of surveillance among mobile populations and migrants will depend on what is being measured and the characteristics of the population.

Collecting the biological specimens for surveillance will depend on what is available to the surveillance team in your region and what is acceptable in the context of cultural and societal norms.

Biological measures

As in most other surveillance systems, biological specimens should be drawn for testing for prevalence of HIV and other STIs. The high sexual risk among mobile persons also makes STI testing a useful and feasible *indicator* for surveillance. For a description of the available STI and HIV tests, refer to the WHO test kit evaluation programme (http://www.who.int/diagnostics_laboratory/evaluations/en/).

- *Syphilis* testing is often the most efficient biological indicator because the standard tests can be done with the same serological specimen as used for HIV testing. The test is relatively inexpensive and widely available.
- Accurate tests for *gonorrhoea* and *Chlamydia* are expensive and usually require a urine specimen.
- *Herpes simplex virus, type 2* (HSV-2) is a marker for lifetime sexual risk. The test, however, it is less available. To be an indicator for sexual risk, the test needs to distinguish HSV-2 from HSV-1.

If, during formative assessment, you found that some mobile persons also inject drugs, biological markers of injection drug use include *hepatitis B core antibody* (HBcAb) and *hepatitis C virus* (HCV) antibody. Tests for HCV may be expensive.

Behavioural measures

Measuring changes in sexual behaviour among mobile populations helps explain trends in HIV and STI prevalence data. Among mobile persons, new behavioural trends may emerge rapidly, particularly when programmes and resources are targeted to promote safe behaviour in this group.

Core *UNGASS* indicators for mobile populations include:

- percentage of the target mobile population, such as refugees or truck drivers, that received HIV testing in the last 12 months and know the results
- percentage of the target population reached by prevention programmes
- percentage of the target population that correctly identify ways of preventing the sexual transmission of HIV and that reject major misconceptions about HIV transmission.

Where appropriate, these indicators may be supplemented with the following additional behavioural indicators:

- knowledge of HIV and STIs
- number and types of sex partners
- condom use with sex partners
- sex with other men
- injection drug use
- history of genital ulcer disease or genital discharge
- STI treatment-seeking history and places where care is sought
- marital status or regular partnership status
- basic demographic characteristics
- the length of time spent away from home and regular sex partners
- where they travel and how often
- city/region/country of origin
- whether they cluster in communities that mimic their home and living conditions, types of social support.

Other indicators also may be appropriate. Your formative assessment will help you determine which measures are of particular importance in your area.

Reference to indicators

Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found in Unit 1.

Indicators recommended by international bodies will not necessarily capture all behaviours relevant to your area. Some questions will be for local use only; for example, exposure to specific prevention programmes or assessing particular risky practises. The formative assessment phase should be used to determine the local questions of greatest relevance to the epidemic in your area. In addition, the wording of the indicators will have to be translated and field-tested in your local languages.

Special Ethical Considerations

There are special ethical issues you must consider when conducting surveillance activities in mobile populations. Being identified as HIV-infected or an *injecting drug user* (IDU) could result in a person being fired from a job or being deported.

An additional ethical concern when including mobile populations in surveillance activities is what may result when a particular social, religious, or ethnic group is identified as having a high prevalence of HIV or risk behaviours. This is particularly important when a high prevalence of HIV is discovered in a refugee, IDP, or immigrant population in an otherwise low-prevalence country.

Obtaining informed consent

You should consider your ability to obtain true *informed consent* when mobile persons may be coerced to participate or not participate by their employer or by their community leaders.

Assuring confidentiality

Confidentiality protects subjects from adverse consequences that may arise from participating in a study or survey. If a person's HIV infection becomes known, he or she may suffer discrimination or *stigma*, or be subject to criminal charges in some situations. Be aware of any particular provisions in your country's laws that may complicate participation. These may include:

- laws prohibiting men to have sex with men
- laws prohibiting injection drug use
- laws requiring reporting of individuals with HIV infection
- laws that protect study results from legal proceedings that could result in jail or deportation.

People asked to participate in a survey or study should understand potential threats to their confidentiality. They should also understand the steps that the investigators will take to minimise the threats. Explaining these issues to them is part of the informed consent process.

Summary

Mobile populations are at high risk both for getting and transmitting HIV and STIs and often serve as a bridging population between female SWs and the general population. Methods for surveillance in migrants are similar to those used in other high-risk populations in this module. Surveillance among mobile populations should be conducted on a regular basis every year and should include biological and behavioural measures. The best way to sample these groups will depend on which specific groups of workers you wish to survey and the places in which you can find them.

NOTES

Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of this appendix. Make any changes you want to make. We will discuss the questions and answers in a few minutes.

Small group discussion

1. List migrant/mobile populations at high risk for HIV in your country.

2. Does your country conduct behavioural and/or sero-surveillance of mobile populations, such as refugees, undocumented labourers, or truck drivers?

3. In your country, who are the *gatekeepers* of this population?

4. In your country, what methods have been used to sample mobile populations?

5. In your country, what behavioural and biological measures have been used when conducting surveillance of mobile populations?

6. In the past five years, has the prevalence of HIV among mobile populations increased, decreased, or remained about the same?

Apply what you have learned/ case study (1)

Try this case study individually or in a group. We'll discuss the answers in class.

Biological and Behavioural Surveillance among Boardland Refugees in Globa

Part 1: Collecting information to plan surveillance activities

Port Marina, with a total population of 10 million people, is a large port city in Globa, a country with a *low-level HIV epidemic*. Due to civil unrest in the neighbouring country of Boardland, a country with a *generalised HIV epidemic*, thousands of documented and undocumented Boardland refugees migrate to Globa each year; many more transit through Port Marina on their way north.

Although the UNHCR administers two closed refugee camps, each for approximately 20 000 Boardland refugees, many undocumented migrants settle in the slum neighbourhoods of Port Marina, where there is a large Boardland community. The following information has been reported:

- Results from routine antenatal clinic (ANC) surveys in Boardland and Globa in 2006 indicate that the prevalence of HIV is significantly higher in Boardland than in Globa.
- Police reports indicate that some female Boardlandis are selling sex to support themselves.
- Information from service providers indicates that many from Boardland do not seek care at hospitals and clinics for fear that their illegal immigration status may result in deportation.

The HIV programme manager decides to conduct a survey among Boardlanders in Port Marina to design interventions to curb the spread of HIV among Boardlanders and to the general population in Port Marina.

The HIV programme manager focuses on Boardlanders in the slum communities because of their potential as a bridging population, bringing HIV infection from high-prevalence areas to an area of lower prevalence. The programme manager decides to undertake a combined biological/behavioural survey, and holds a meeting with her HIV surveillance team to plan for the survey.

- What information is required for planning the survey?

- How might the HIV surveillance team obtain this information?

Part 2: Choosing a sampling approach

To obtain background information for designing a behavioural survey, the HIV surveillance team review several documents, including published literature, reports from the UNHCR, the Red Crescent Society, and other organisations that provide services to Boardland migrants. Several *key informants* are also contacted, including prominent members of the Boardland community in Port Marina, persons from the Ministry of the Interior, persons from the Ministry of Immigration, and cafe and other business owners in Boardland communities. Interviews of key informants are conducted using open-ended questions.

The HIV surveillance team discover that:

- The UNHCR camps are closed camps and no mixing occurs between Boardlanders in the camps and the general population of Port Marina.
- A UNHCR study at one of the closed camps found the prevalence of HIV among ANC attendees was 1.5%.
- There are three neighbourhoods in Port Marina that are primarily inhabited by Boardlanders.
- Many Boardlander immigrants work as day labourers and congregate on specific street corners to wait for employment.
- There are many Boardlander-owned cafes and restaurants in these neighbourhoods that Boardland immigrants patronise.
- Some Boardland women work as SWs and have Boardland and non-Boardland clients.
- Injection drug use is not common among Boardlanders.

1. What sampling scheme can be used to select representative respondents to be included in the survey?

Part 3: Sampling and collecting biological and behavioural data

A variety of sampling approaches are appropriate for sampling Boardland immigrants in Port Marina, Globa. The team weigh the pros and cons of each sampling approach. Because the team were able to learn that many Boardland migrants congregate in identifiable locations in large numbers, they decide to employ TLS.

1. What are the advantages and disadvantages of this approach?

2. If only men congregate in identifiable locations, what are the limitations of using TLS?

3. If the surveillance team were to include Boardland refugees in the closed refugee camps, which sampling approaches would be appropriate?

4. What behavioural variables should be collected?

5. What biological variables should be collected?

Part 4: Collecting survey information

Although TLS requires mapping and time-consuming ethnographic work and may only reach a sub-set of the target population, it allows for a probability sample of the Boardland immigrants.

Had the surveillance team decided to include the refugees in the closed UNHCR camps, the team could have employed simple random sampling or systematic sampling, provided that UNHCR granted the team access to the camp and the refugees.

After explaining the purpose of the surveillance activity and obtaining informed consent, members of the surveillance team collect urine and blood samples from participants, which are then tested for:

- HIV-1
- *Herpes simplex virus-2* (HSV-2)—a marker of lifetime sexual risk, for example, multiple sex partners
- syphilis
- gonorrhoea.

Interviewers administer semi-structured questionnaires to the refugees to assess sexual risk behaviours. Variables collected include:

- socio-demographic information, such as age, marital status, employment history, point of origin
- types of female sex partners in the past year
- *men who have sex with men* (MSM) activity
- condom use
- history of diagnosis with STIs, current symptoms of STIs.

Part 4: Collecting survey information, continued

The survey produces the following biological results:

- HIV prevalence: 2.75% (11/400)
- HSV-2 prevalence: 40% (160/400)
- syphilis prevalence: 5% (20/400)
- gonorrhoea prevalence: 3% (12/400).

Test results are returned to survey participants and those with positive test results are referred to appropriate services.

The survey produces the following behavioural results:

Risky sexual behaviour is common, including low condom use with non-marital partners. Premarital and extramarital sex are both common. Both married and non-married Boardlanders report multiple sex partners, with a small number of female Boardlanders involved in sex work with Boardlander and non-Boardlander clients. Only 20% of those engaged in sex work reported they ever used a condom, and 5% consistently used condoms with non-cohabitating, non-marital partners.

1. What interventions should be initiated based on these results?

Part 5: Epilogue

Findings of this study are consistent with the results of other studies. Many male Boardland migrants engage in high-risk behaviours and many did not have their last genital symptoms treated. Additionally, a sub-set of Boardland women work as SWs in Port Marina with non-Boardland clients, thus serving as a bridging population to the general population of Globa.

Given the very low levels of HIV in Globa, targeting Boardland immigrants and refugees with behaviour-change interventions could be an important means of avoiding an HIV epidemic.

Based on these findings, the Globa Minister of Health directs the HIV programme manager to implement the following measures in Port Marina:

1. Create condom-use campaigns by engaging peers and NGO outreach workers to educate Boardland immigrants about consistent condom use with SWs and regular partners.

2. Engage migrant populations in knowledge-building activities regarding the modes of HIV transmission.

3. Improve the service provided to refugees by:

    a. establishing voluntary counselling and testing (VCT), reproductive health services, STI treatment programmes and psycho-social counselling programmes for migrants
    b. hiring medical professionals who speak the language(s) of the migrant populations
    c. ensuring that information gathered by people seeking treatment and care is not used by the Ministry of Immigration for deportment purposes.

4. What are some of the risks Boardlanders living in Port Marina face if the results of this study are published and made available to the general population?

Apply what you have learned/ case study (2)

Biological and Behavioural Surveillance among Truck Drivers in Globa

Part 1: Collecting information to plan surveillance activities

Sadcity, with a total population of 15 million people, is the capital of Globa. The Northern District of Globa borders Boardland and is thought to be a common drug trafficking area. Port Marina, to the south, is Globa's major deep-water port and a docking place for merchant marines, cruise ships, and local fishing vessels.

Sero-prevalence surveys conducted in Sadcity have consistently found low HIV prevalence. Similar surveys conducted over the past five years, however, have found that prevalence levels of HIV among IDUs in the Northern District and STIs among female SWs in Port Marina are rising at an alarming rate.

The Globa Minister of Health, concerned that HIV will spread from these high-risk groups to the general population, advises the regional HIV programme manager to investigate the spread of HIV in the country.

The HIV programme manager decides to focus on truck drivers because of the role the trucking industry plays elsewhere in the spread of HIV and the documented high-risk behaviours of truck drivers globally. She decides to undertake a combined biological/behavioural survey among truck drivers in Globa and holds a meeting with her HIV surveillance team to plan for the survey.

- What information is required for planning the survey?
- How might the HIV surveillance team obtain this information?

Part 2: Choosing a sampling approach

To obtain background information for designing a behavioural survey, the HIV surveillance team review several documents, including published literature, reports of NGOs, reports from trucking companies, and clinic records from roadside health centres. Key informants are interviewed using open-ended questions. Key informants include owners and managers of trucking companies, truck drivers and helpers, Ministry of Transport, the trucking union, and staff of roadside health centres.

Through discussions with key informants and a review of the available literature, the surveillance team discover that there are 140 trucking companies in Globa that employ approximately 20 000 truck drivers. All trucking companies have offices in Sadcity, where truck drivers must report frequently to receive their trip assignments. The HIV surveillance team also discover that there are three main categories of trucking companies and that, due to union negotiations, each trucking company serves either:

- a long-distance route between Sadcity and Northern District, which borders Boardland
- a medium-distance route between Sadcity and Port Marina in the south of the country
- local routes between Sadcity and the surrounding areas.

The HIV surveillance team conduct a census of the trucking companies in Globa to determine which companies employ which types of drivers (long-distance, medium-distance, or local) and how many truckers each company employs. The surveillance team learn that 20 companies employ a total of 10 000 long-distance drivers, 100 companies employ a total of 4 000 medium-distance drivers, and 20 companies employ a total of 6 000 local-route drivers.

- What is an adequate sample size to detect an increase in consistent condom use (defined as use of condoms during every episode of vaginal intercourse in the preceding three months) with SWs from 10% in the current year to 20% if the survey is repeated in two years? (Refer to table with the sample size options).

The most conservative sample size to detect an increase of 10 percentage points (10%-20%) in the proportion of truckers who reported consistent condom use (with 80% power of detecting a change of this magnitude at the 95% confidence level) is 395 truckers per survey year. The final sample size is rounded to 400 per survey year.

- What sampling scheme can be used to select representative respondents to be included in the survey?

Part 3: Sampling and collecting biological and behavioural data

A variety of sampling approaches are appropriate for sampling truck drivers in Globa. Because the team were able to construct a list of all of the trucking companies, as well as information on how many drivers each company employs, the HIV surveillance team decide to employ *probability proportional to size* (PPS) sampling scheme, in which types of truck drivers are sampled proportionate to the size of the different groups of truck drivers (long-distance, medium-distance, or local).

In stage 1, the team stratify the sampling by category of truck driver. To ensure that the sample reflects the actual composition of the truckers, the required number of truckers from each category is estimated:

- 200 long-distance drivers should be in the sample, as 50% of drivers are long-distance drivers
- 80 medium-distance drivers should be in the sample, as 20% of drivers are medium-distance drivers
- 120 local-route drivers should be in the sample, as 30% of drivers are local-route drivers.

In stage II, the survey team determine that their budget allows them to make 40 sampling trips and survey 10 truck drivers per trip. Based on this estimate, and considering that each company only employs one type of driver, all 20 long-distance trucking companies are contacted; eight medium-distance companies are randomly selected; and 12 local-route companies are contacted.

With help from the selected trucking companies, the surveillance team randomly select 10 truck drivers from each selected trucking company. A total of 400 truckers are successfully recruited.

- Describe how you would randomly sample 10 truck drivers from each company.

- What behavioural variables should be collected?

- What biological variables should be collected?

Part 4: Collecting survey information

Between January and April of 2008, the fieldworkers visit the selected trucking company's office at the Sadcity truck stand to recruit subjects. The Sadcity truck stand is selected as the best site for recruitment as all companies have offices there and all drivers must visit the office to receive their trip assignments. Assuring the participants that confidentiality will be maintained, the fieldworkers explain the purpose of the study to the drivers and obtain verbal informed consent.

Members of the surveillance team escort the recruited drivers to the local roadside STI clinic for biological and behavioural data collection.

Male clinic staff members collect urine and blood samples from participants, which are then tested for:

- HIV-1
- HSV-2, a marker of lifetime sexual risk, for example, having had multiple sex partners
- syphilis
- gonorrhoea
- hepatitis C, a marker for injection drug use.

Interviewers administer *semi-structured questionnaires* to the truck drivers to assess sexual and injecting risk behaviours. Variables collected include:

- socio-demographic information, such as age, marital status, employment history
- alcohol and drug use
- types of female sex partners in the past year
- *men who have sex with men* (MSM) activity
- condom use
- history of diagnosis with STIs, current symptoms of STIs
- injection drug–use behaviours, such as types of drugs injected, frequency, needle-sharing, and use of sterile equipment.

The survey produces the following biological results:

- HIV-1 prevalence: 2.75% (11/400)
- HSV-2 prevalence: 40% (160/400)
- syphilis prevalence: 5% (20/400)
- gonorrhoea prevalence: 3% (12/400)
- hepatitis C prevalence: 12% (48/400).

Part 4: Collecting survey information, continued

The survey produces the following behavioural results:

Risky sexual behaviour is common, with few truckers reporting consistent condom use despite having large numbers of sexual partners. Both premarital and extramarital sex are common. Both married and non-married truckers report multiple sex partners, often with SWs.

Nearly 10% report male-male sex ever and 15% report injection drug use within the last year. Overall, condom use with non-marital partners is low. Only 20% report they ever used a condom and 5% consistently used condoms with non-cohabitating, non-marital partners. No subject who reports having sex with another man reports using condoms.

Marked differences are found between the three categories of truckers.

Long-distance drivers (n = 200):
- mostly single, young
- high rates of injection drug use
- reported sharing of syringes and other injection equipment
- some sexual contact with SWs along trucking route
- 24% prevalence of hepatitis C (48/200)
- 5% prevalence of HIV-1 (10/200)
- three cases of hepatitis C/HIV co-infection.

Medium-distance drivers (n = 80):
- single and married
- high level of interaction with SWs in port of Khalji-al-Akbar
- high prevalence of HSV-2 (80%), gonorrhoea, and syphilis
- no reported injection drug use
- 1.25% HIV prevalence (1/80)
- Most with HIV also had HSV-2; many also had other STIs.

Local-route drivers (n = 120):
- mostly married and many with multiple wives and/or regular sex partners in different locations
- little contact with SWs
- high prevalence of untreated gonorrhoea and syphilis
- no reported injection drug use
- no HIV cases.

1. What interventions should be initiated based on these results?

Part 5: Epilogue

Findings of this study are consistent with the results of other studies. Most trucker drivers surveyed engaged in high-risk behaviours and many did not have their last genital symptoms treated.

Given the very low levels of HIV in Globa, targeting truck drivers with behaviour-change interventions could be an important means of avoiding an HIV epidemic.

Based on these findings, the Globa Minister of Health directs the HIV programme manager to implement the following measures:

- To create 100% condom-use campaigns in port-area brothels; engaging peers and NGO outreach workers to educate truck drivers about consistent condom use with SWs and regular partners

- To establish harm-reduction programmes for IDUs and provide sterile injecting equipment to IDU truck drivers at the large truck stops along the trucking routes between Sadcity and the Northern District

- To establish workplace-based STI screening and HIV education for local-route drivers.

- To improve the service provided at roadside STI clinics by ensuring drug supply and training staff on proper STI management.

NOTES

Unit 6

Street Children

Overview

What this unit is about

This unit describes the background and special considerations for conducting behavioural and biological HIV surveillance among street children.

Warm-up questions

1. What are some of the reasons why street children may be considered vulnerable to HIV?

   a.

   b.

2. List three possible places where you would expect to find large numbers of street children.

   a.

   b.

   c.

3. List two organisations with which you can form alliances as you develop your HIV surveillance system for street children.

   a.

   b.

Introduction

What you will learn

By the end of this unit, you should be able to:

- understand the role of street children in the HIV epidemic
- describe options for sampling of street children for surveillance
- describe the special ethical considerations associated with conducting HIV surveillance activities among street children.

Background

Definitions

The term "*street children*" is often used to describe children who live and/or work on the streets. The United Nations Children's Fund (UNICEF) has defined two main categories of street children:

- Children **on** the street—those engaged in economic activity, such as begging or vending. The children belonging to this group often return home to their families at the end of the day and contribute to the family income.
- Children **of** the street—those who actually live on the streets.

Children of the street often do not have strong familial ties. For the purpose of *surveillance*, street children may include all persons who are under the age of 18, or only those between ages 12 and 18 years. Depending on the laws in your country about research with minors, conducting *biological surveillance* and/or *behavioural surveillance* may not be possible among all age groups. Conducting a *formative assessment* and investigating your country's laws about research with minors will help you determine the age groups you can and should include in your surveillance activity.

Street children often live under challenging conditions and are marginalised from mainstream services and society. Sub-populations of street children at risk for HIV infection include orphaned, homeless, runaway, or neglected children who live chiefly in the streets without adequate protection, supervision, or direction from responsible adults.

Contributing factors

Factors that can contribute to children being on the street:

- Economic hardship—begging to support oneself or family
- The lure of cities—youth may run away from families in rural areas
- Social conflict and emergencies—natural disasters, political conflicts, and war may generate street children
- Orphan status—Parents may have died from war and conflict
- Divorce or separation of parents—illegitimate children also may become street children.

Role of street children in the HIV epidemic

Street children have a higher risk of acquiring HIV, as they:

- do not receive reproductive health education and other school-based services
- may have low self-esteem, which can lead to *risk behaviours*
- face *stigma* and discrimination that prevent them from adopting risk-reduction behaviours
- may have access to drugs, which increases the likelihood of risk taking
- are more likely to experiment with drugs and alcohol
- may be sexually exploited or involved in sex work.

Street children often are more likely than their elders to engage in high-risk behaviour, making them more susceptible to the infection. Reasons for increased risk-taking behaviour among youth include:

- lack of information
- peer pressure
- inability to calculate risk
- low perception of risk
- economic pressures
- inability to refuse unprotected sex
- limited availability of or access to condoms
- lack of youth-friendly services.

Role of street children in the HIV epidemic, continued

The types of risks and social factors underlying HIV infection among street children are varied. Street children are at risk of acquiring HIV because they:

- are often sexually active
- may have multiple sex partners, including *sex workers* (SWs)
- may sell sex in exchange for goods or money
- may be sexually abused
- may sniff glue and/or smoke hashish or marijuana
- may inject drugs
- have less access to prevention information through schools
- may be involved in gangs and/or drug trafficking
- are unlikely to receive appropriate medical care.

By targeting street children through behaviour-change interventions, several countries have successfully decreased national HIV *prevalence* levels. To create appropriate interventions, HIV surveillance of high-risk youth is crucial.

Prevalence of HIV among street children

There is limited data on the prevalence of HIV among street children. From what is known, it varies by country and region, as illustrated by the following data:

- Of 102 street children (<15 years old) included in a cross-sectional study in Tehran, Iran, all were HIV-negative, three were positive for hepatitis B surface antigen, and 15 were positive for hepatitis B surface antibody. (Vahdani, 2006)
- In Cairo, Egypt, among the 600 street children (ages 12–17 years) surveyed between May and August 2006, the prevalence of HIV was zero. (HIV/AIDS BSS Summary Report, 2006)
- A cross-sectional assessment conducted during January-May 2006 among street youth 15-19 years old revealed of the 313 participants that 37.4% were HIV infected (Kissin D et al. HIV seroprevalence in street youth, St. Petersburg, Russia, AIDS 2007)
- Among street youths over 15 years old in Bolivia in 2002, overall HIV prevalence was 3.5% (11/313), higher among those recruited in the street, lower among those recruited in centres for the homeless. (Lambert et al. Street Youths Are the Only High-Risk Group for HIV in a Low-Prevalence South American Country)
- India has the largest concentration of street children in Asia, with the highest number in Mumbai, the commercial capital of India. One study attempted to understand the HIV/AIDS risk-taking behaviour and the

Prevalence of HIV among street children, continued

treatment-seeking behaviour among street children in Mumbai. A survey was conducted using a structured questionnaire among 1,650 children, and 15 focus group discussions and 15 in-depth interviews were conducted. No one surveyed had ever used a condom and about 67% of the girls had experienced sex with unknown person. STIs are very common and treatment-seeking is very low; treatment often is sought from “quacks”. (HIV/AIDS risk taking behaviour among street children in Mumbai. Gurumurthy R; International Conference on AIDS. Int Conf AIDS. 2000 Jul 9-14; 13: abstract no. TuPpD1269. R. Gurumurthy, International Institute for Population Sciences)

- Aide Médicale Internationale (AMI), a French non-governmental organisation, has counted over 2,120 street children in Port-au-Prince, Haiti, some as young as 10 years old. A socio-medical programme launched by AMI in 2004 uses mobile clinics to bring healthcare and psychological support to them. STIs account for around 30% of consultations at the mobile clinic (http://en.afrik.com/article12363.html).

Role of street children in surveillance

Persons under the age of 18 years account for the largest portion of the population. It is crucial to identify and track high-risk groups within this population.

In many parts of sub-Saharan Africa, the increase in the population of street children may be due to the increase in numbers of AIDS orphans. Most AIDS orphans who have to fend for themselves, for different reasons, engage in the exchange of sex for money, clothes, food, and shelter. (Promoting street kids participation in HIV/AIDS prevention in sub-Saharan Africa (Adaramola SE, Ebenezer A, Omotunde PA, Oyekanmi TO; International Conference on AIDS [15th: 2004: Bangkok, Thailand] *Int Conf AIDS.* 2004 Jul 11-16;15:abstract no. D10451).

Because of the high-risk behaviour and ability to make long-lasting behavioural changes, many special programmes and interventions are specifically targeted toward street children and other youth. These programmes include:

- mass media campaigns
- promotion of youth-friendly health services
- condom promotion use and life skills
- *voluntary counselling and testing* (VCT) for HIV and *sexually transmitted infections* (STIs).

Because young people often are powerful agents for change when given the appropriate tools and support, it is crucial to have surveillance in place that will help monitor any specific behaviour changes observed in youth groups.

Conduct a Formative Assessment

Consider where to find street children

Because street children are composed of a many different sub-groups, HIV prevalence may differ considerably among groups existing relatively closely within a country or even within a city. Identifying points of access and forming *alliances* with organisations and persons trusted by the different sub-groups will help you understand more fully the culture and diversity of street children in your area.

Surveillance requires gaining access to a full range of street children and to areas where street children can be found. This may be difficult when considering each sub-group's different characteristics. Findings from the pre-surveillance assessment should prove helpful in focusing the search. To aid in locating and accessing street children, consider:

- identifying and interviewing people known to have regular contact with street children
- visiting areas where the children are known to congregate
- collaborating with organisations that provide education, food, and shelter to street children, such as religious organisations and civil society organisations.

Consider where to find street children, continued

Possible organisations that can help you locate and access street children include:

- governmental bodies, such as the Ministry of Social Development and the Ministry of Youth and Sports
- the United Nations Children's Fund (UNICEF)
- the United Nations Populations Fund (UNFPA)
- the Red Cross and Red Crescent societies
- Save the Children
- day centres for street children
- youth scouts
- OXFAM International
- local and international *non-governmental organisations* (NGOs) that work with street children
- local sports clubs.

Other sub-groups of street children, such as child SWs, factory workers, and soldiers, may require more extensive formative assessment before they are located. These sub-groups may be more easily accessed by forming alliances with adults or older youth who are in charge of them. Some examples include:

- influential current and former SWs, factory workers
- police
- leaders of youth gangs and begging groups
- governmental organisations and NGOs that have youth-targeted HIV prevention and care programmes
- national and international advocacy groups dealing with issues relating to street children.

These people and organisations also can assist later in implementing surveillance activities. Former adolescent SWs can be hired and trained as recruiters or interviewers in difficult-to-access areas.

Conduct ethnographic mapping

This comprehensive description is used to guide broadly where and when street children can be found and recruited for surveillance activities and what sub-groups can be found in different areas. More specifically, detailed *ethnographic mapping* can be used to produce a *sampling frame* or comprehensive roster representing street children or a particular sub-group in your area. This sampling frame provides the basis for some *probability-based sampling* methods.

The locations where street children spend most of their time will differ by sub-group. To locate street children, identify areas where young people tend to congregate. These include:

- parks
- markets and shopping centres
- city centres and squares
- tourist sites
- train and bus stations
- around mosques
- near restaurants
- near religious ceremonies
- street corners
- busy intersections
- under bridges
- drop-in centres for street children.

Due to various legal issues surrounding many of the sub-groups, it is unlikely that there is any formal registration system for street children. Depending on the country or region, however, street children may be registered as SWs or labourers. Rosters of street children also may be available from NGOs, religious organisations, drop-in centres, and other agencies that provide services to street children. It is important to note that these lists are rarely separated into adult and youth categories, making it difficult to obtain a representative sample.

Selecting a Sampling Method

Most-at-risk populations (MARPs) that are hard to reach, such as street children, may be sampled using either probability sampling or *non-probability sampling* (also referred to as *convenience sampling*). Depending on the organisation, accessibility, and the extent to which street children are *networked*, different sampling methods may be more or less feasible. Although non-probability sampling, such as *snowball sampling*, is easier to conduct than probability sampling because a sampling frame is not needed, data collected through non-probability methods can introduce *bias* into the data. This can occur due to differences in HIV prevalence or risk behaviours between different sub-populations or sub-groups. Probability and quasi-probability sampling methods can be used to obtain more representative samples of street children.

Probability sampling techniques like *time-location sampling* (TLS) and *respondent-driven sampling* (RDS) may be used to sample hard-to-reach street children.

Time-location sampling

Time-locations sampling (TLS) may be used to sample street children when they tend to gather or congregate in identifiable and accessible locations, such as certain street corners, markets, and transportation centres. In TLS, the street children-frequented sites, which are found through ethnographic mapping or pre-surveillance activities, are used to develop a sampling frame from which a probability sample of sites and time periods are chosen. Because these locations may change over time, you should develop a new sampling frame for each round of surveillance.

Mapping the locations where street children can be found also will help you decide where to implement future interventions.

Respondent-driven sampling

Certain sub-populations of street children do not congregate in identifiable and accessible locations and are not adequately represented by TLS. Respondent-driven sampling, an adaptation of chain-referral sampling, is based on a dual incentive structure in which participants are rewarded for being interviewed and for recruiting their peers. When using RDS to sample hard-to-reach or mobile street children, incentives should not be too weak or too strong.

- If incentives are too weak, participants may think the compensation is not worth the time it would take to recruit their peers.

Respondent-driven sampling, continued

- If incentives are too strong, bias can be introduced, as the participants may try to keep the incentives distributed solely within their own peer group.

Food items, clothing, and other useful, in-kind (non-monetary) items are often used as incentives when conducting RDS among children and adolescents. Organisations working with street children can help you determine appropriate incentives.

As the definition of street children may vary, your inclusion and exclusion criteria should be very clear in the first wave of recruitment so that youth understand which other youth to recruit.

An RDS study in Accra, Ghana, and Bamako, Mali was conducted to get a sample of street children proportional to the population, and to give accurate characteristics of the street children population in the two locations. Information about this study can be accessed from http://www.fafo.no/pub/rapp/474/474.pdf, Hatloy A and Huser A. Identification of street children in Bamako and Accra. Fafo 2005.

RDS may not work in all settings. In settings where street children neither congregate in identifiable locations nor have strong social networks, using a non-probability sampling approach, such as snowball sampling, may be your only option. Your formative assessment will provide you with the information necessary to determine which sampling approaches are feasible.

Priorities for local AIDS control efforts

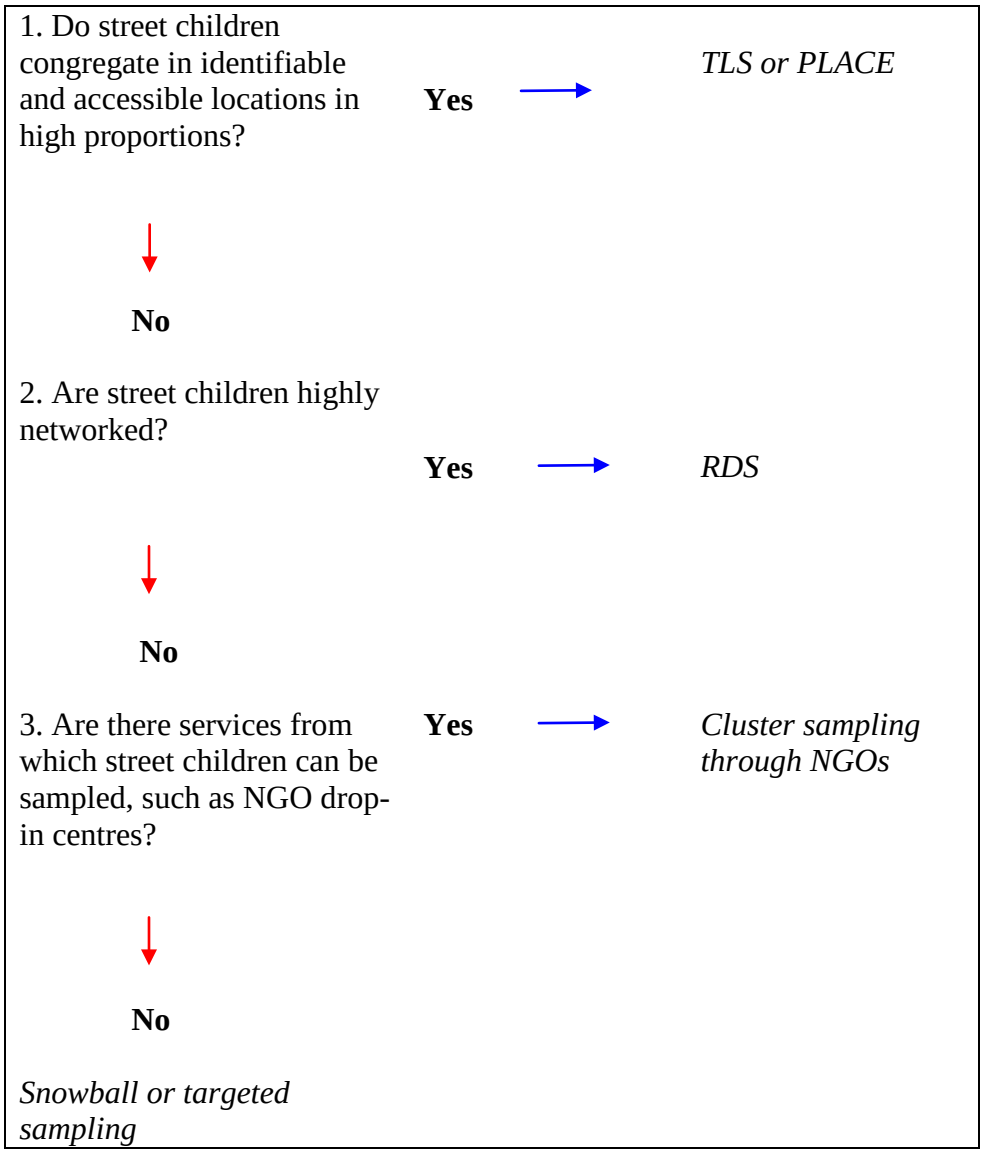
The *Priorities for Local AIDS Control Efforts* (PLACE) protocol is a *rapid assessment* tool used to identify areas of high HIV transmission. It formalises the collection of information in high-transmission areas. PLACE uses *key informants* to identify locations where people meet new sex partners, then conducts interviews at the site to characterise the people who congregate there and to map sites. Identifying high-transmission areas and places where people meet new sex and injecting partners also will help you determine where to implement behaviour-change interventions and other programmes targeted at street children.

For further information, please refer to:
http://www.cpc.unc.edu/measure/leadership/place.html

Priorities for local AIDS control efforts, continued

Figure 6.1 will help you select an appropriate method for sampling street children in your area.

Figure 6.1. Selecting sampling methods for street children.



Additional information on the sampling methods that may be used to sample street children is discussed in the module entitled "Surveillance of HIV Risk Behaviours."

Measures and Indicators

Biological measures

Measuring HIV prevalence among street children is important to surveillance. The high sexual risk among many of the sub-groups makes STI testing a good *indicator* for surveillance. For information on the available STI and HIV tests, refer to the WHO test kit evaluation programme at http://www.who.int/diagnostics_laboratory/evaluations/en/

- *Syphilis* testing often is the most efficient biological indicator of unprotected sexual intercourse; the standard tests can be done with the same serological specimen as is used for HIV testing. The test is relatively inexpensive and widely available.
- *Gonorrhoea* and *Chlamydia* tests usually require a urine, rectal, or pharyngeal specimen.

Behavioural measures

Measuring changes in sexual behaviour among street children helps explain trends in HIV and STI prevalence data. Among street children, new behavioural trends may emerge rapidly, particularly when programmes and resources are targeted to promote safe behaviour in this group.

Indicators that assess sexual risk include:

- correct identification of ways to prevent the transmission of HIV and rejection of major misconceptions about HIV transmission
- age of *sexual debut*
- history of coerced sex
- condom use during last sex
- sex with multiple partners
- exposure to interventions
- access to HIV services and healthcare
- psychological indicators to assess history of trauma
- the use of transactional sex.

In areas where there is suspected overlap between street children and other MARPs, such as SWs, MSM, or *injecting drug users* (IDUs), consider using indicators that assess high-risk behaviours among these groups.

Behavioural measures, continued

The indicators that may be appropriate in situations where there is suspected overlap between street children and other high-risk groups are presented in Table 6.1, below.

Table 6.1. Additional indicators to include when there is suspected overlap between street children and other high-risk groups.

Group	Indicators
Sex workers (SWs)	▪ venue of sex work ▪ number of paying customers ▪ condom use with paying customers
Injecting drug users (IDUs)	▪ frequency of injection drug use ▪ sharing of needles, syringes, or other injecting equipment ▪ types of drugs injected ▪ history of imprisonment
Men who have sex with men (MSM)	▪ number of male sex partners ▪ frequency of *unprotected anal intercourse (UAI)* ▪ frequency of *unprotected receptive anal intercourse (URAI*)

Reference to indicators

Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found in Unit 1.

Special Ethical Considerations

Because street children are young and often involved in activities such as prostitution or child labour, they are often stigmatised and are considered a *vulnerable population*. Their participation in surveillance activities may place them at risk for harm and discrimination. These risks include:

- loss of anonymity, such as inadvertent identification as a drug user, SW, or undocumented labourer
- inadvertent disclosure of HIV status
- negative reaction and consequences in response to publicised results.

It also may be difficult to obtain true *informed consent*, due to the lower education and literacy levels common among street children.

Assuring confidentiality

Anonymity protects subjects from the negative consequences that may arise from participating in a study or survey. Be aware of any of your country's laws that may complicate participation. These may include:

- laws prohibiting working under a certain age
- laws prohibiting sex work or sex work under a certain age
- laws prohibiting drug use
- laws requiring reporting of individuals with HIV infection
- laws prohibiting sex under a certain age or outside of marriage.

People asked to participate in a survey or study should understand potential threats to their anonymity. They also should understand the steps that the investigators will take to minimise the threats. Explaining these issues to them is part of the informed consent process.

Steps you can take to minimise threats to anonymity may include:

- conducting anonymous interviews with street children in private settings
- collecting no identifying information about street children
- limiting access to all information study data to authorised study personnel only
- keeping study documents in a locked, limited-access room.
- having all staff sign confidentiality forms and undergo training in research ethics.

Working with adolescents

Different countries have different laws and standards about when an adolescent can participate in research involving sexual behaviours. There also are different laws regarding the age of majority and when parental consent is required. Familiarise yourself with these laws in your country as part of your initial formative assessment efforts. Generally, surveillance tries to minimise the number of participants in the age range 15–18, and avoids including those under 15. If it is necessary to include children under the age of 15, special guidance on research with children should be sought.

Emancipation of minors is a process that occurs when a court or another body given that authority declares that someone who is still a minor is nevertheless to have the legal rights of an adult and to be free of any authority from their parent or other legal guardian. Each country has its own laws regarding the emancipation of minors, and many countries deem a minor to be automatically emancipated if they marry. It may be necessary to check your country's laws regarding parental consent and the age of majority, as some street children may be considered minors, and obtaining consent from their parents may be difficult.

The World Medical Association has developed the Declaration of Helsinki as a statement of ethical principles to provide guidance to persons participating in research involving human subjects. The Declaration of Helsinki provides ethical guidance for research activities involving minors and states:

> When a minor child is able to give assent to decisions about participation in research, the investigator must obtain that assent in addition to the consent of the legally authorised representative.

Further information on the ethical principles included in the Declaration of Helsinki is available at: http://www.wma.net/e/policy/b3.htm

Summary

Depending on the organisation and accessibility of street children in your area, different sampling methods may be more or less feasible. Additionally, appropriate behavioural indicators will vary depending on the situation and sub-populations of street children in your area. You should be aware that different countries will have different laws and standards about when an adolescent can participate in research involving sexual behaviours and when parental consent is required. If you plan to include children under the age of 15 years in your surveillance activities, you should seek special guidance on research with children.

NOTES

Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of this unit. Make any changes you want to make. We will discuss the questions and answers in a few minutes.

Small group discussion

Get into small groups to discuss these questions.

1. Does your country conduct behavioural and/or sero-surveillance of street children?

2. In your country, who are the *gatekeepers* of this population?

3. In your country, what methods have been used to sample street children?

4. In your country, what behavioural and biological measures have been used when conducting surveillance of street children?

5. In the past five years, has the prevalence of HIV among street children increased, decreased, or remained about the same?

Apply what you have learned/ case study

Conducting Behavioural Surveillance among Street Children in Great Gorge, Globa

Part 1: Collecting information to plan surveillance activities

Great Gorge, with a total population of 5 million, is the economic and administrative capital of Globa, a large country in the Eastern Mediterranean.

In 2007, data from STI surveillance found that number of new diagnoses of Chlamydia among adolescents had doubled since 2000. Alarmed by this information, the Ministry of Health developed a package of youth-targeted, evidence-based interventions to reduce HIV, including a national multi-media prevention campaign of billboards, leaflets, and radio and television broadcasts.

The Commissioner of Public Health for the Great Gorge metropolitan area is alarmed by recent NGO reports that an increasing number of street children, some as young as 15 years old, are presenting at urban public health centres with STIs and symptomatic HIV infection. She worries that the interventions and media campaign might not be reaching the street children or have not been effective in preventing HIV infection among these youth.

The Commissioner of Public Health directs the HIV Programme Manager to undertake a survey in Great Gorge to determine the sexual and injecting behaviours of street children and to assess whether they have been exposed to the multi-media HIV prevention campaign. She holds a meeting with her team of epidemiologists and social workers to plan for the survey.

1. What information is required for planning the survey?

2. How will the HIV team obtain this information?

Part 2: Building key alliances with community networks involved with street children

Prior to conducting the survey, the HIV team need to conduct pre-surveillance activities, such as ethnographic mapping, to decide who they want to survey, where these youth can be found, what questions to ask, and the ethical considerations of undertaking such a survey.

To obtain background information for designing a behavioural survey, the HIV team review several documents, including peer-reviewed articles, government reports, NGO reports, clinic records of the public and private clinics, and reports from the police department. Several key informants are contacted, including current and former street children, railway station employees, shop keepers, police, NGO managers, and outreach health workers. The HIV team collect information on the locations where street children sleep, work, and congregate and which public health services and NGOs operate in the area.

Through discussions with current and former street children, the HIV team realise that street children are highly distrustful of outsiders, including researchers, and are fearful that involvement in research activities may lead to the destruction of their illegal squatter settlements or to their arrest or both. The team decide that to access street children, they must enlist the support of gatekeepers whom the street children know and trust.

1. Who are important gatekeepers that can help the HIV team gain access to the street children in Great Gorge?

2. What actions can the HIV team take to address the street children's distrust?

Part 3. Ethical considerations

Through discussions with current and former street children and managers of NGOs working with street children, the HIV team learn that many of the youth are organised in cliques (or groups), with certain cliques living and working as a team. Using these contacts, the HIV team meet with "senior" street children, who have influence among other street children, NGO managers, and the police in the area.

A briefing meeting is organised, at which the HIV programme manager informs the *stakeholders* about the need for and purpose of the behavioural survey. The expected outcome of the survey is explained to the audience.

With a verbal assurance of the cooperation of the stakeholders and assurance from the police that they will not arrest street children participating in the survey or destroy their settlements, the HIV team can move to the next step.

1. What are the special ethical considerations related to conducting HIV surveillance among street children?

2. What actions can you take to safeguard the well-being of the street children whom you want to participate in your surveillance activity?

3. What kinds of incentives should the HIV team offer the street children who participate in the survey?

Part 4. Choosing a sampling approach

Discuss special ethical considerations and how one might go about establishing an ethics committee or a group that advocates for the rights of the street children who participate.

1. What sampling methods are appropriate for sampling street children in Great Gorge?

2. What are the advantages and disadvantages of each approach?

3. How would the HIV team construct their sampling frame?

Part 5. Collecting behavioural data

The HIV team consider their sampling options and determine that they could:

- conduct targeted sampling
- conduct TLS at locations where street children congregate
- use snowball sampling
- conduct RDS.

The team weigh the pros and cons of each approach and consider the following:

- Targeted sampling requires knowing the venues and then developing a sampling frame based on quotas, but is not a probability-based sampling method.
- Snowball sampling is easier to conduct and requires fewer resources than TLS or RDS because it does not require a sampling frame. Like targeted sampling, snowball sampling is not a probability-based sampling method.
- RDS and TLS are probability-based sampling methods that have more external validity than either snowball sampling or targeted sampling.

Given that street children sleep, work, and congregate in identifiable and accessible locations, the availability of adequate resources and the strengths of TLS as a probability sampling method, the team decide to conduct TLS to obtain a representative sample of street children in Great Gorge.

The HIV team construct a list of sites where street children live, work, and meet. These sites include squatter settlements where many street children sleep, bus stations, train stations, busy intersections, markets where street children beg and hock goods, and parks where they congregate. The team visit these venues and counts the numbers of street children present at specific times. The team statistician determined that the HIV team needs to survey a total of 600 street children; thus, the HIV team decide to use a two-stage cluster sampling design. In Stage I, 20 locations are randomly selected using a list of random numbers. In Stage II, a fixed number of 30 street children are selected from each selected site at a randomly selected three-hour time period on a randomly selected day of the week.

Although the HIV team discuss providing financial incentives, for ethical reasons they decide to give a packet of biscuits and a hot meal as the incentive to participate.

1. What behavioural variables should be collected?

Part 6. Results

At the randomly selected locations and times, trained interviewers explain the purpose of the study to the youth and obtain verbal consent. Confidentiality is assured. The interviews are conducted in private and in a non-coercive manner. Personal identifiers are not collected.

Trained interviewers administer a pre-tested, semi-structured questionnaire to recruited youth to assess HIV risk behaviour, HIV-related knowledge, and exposure to interventions.

The questionnaire includes queries on demographics and the context of street life, including age, gender, household information, lifetime years on the streets, literacy and educational information, current school attendance, and highest grade completed. Participants are asked about lifetime history of sexual intercourse, age of first intercourse, frequency of condom use, if they had ever exchanged sex for money, had experienced any kind of sexual abuse in the streets, had experienced any kind of sexual abuse in the home. They are asked about their alcohol and illicit drug use. Youth are asked about the number of sexual partners they had in the previous year, whether they were diagnosed with any STIs, and whether they had any unprotected sex under the influence of drugs or alcohol. The HIV-related knowledge and information section included items asking about any HIV testing history and whether they could correctly identify condom use as a means of preventing HIV transmission. To assess the youths' recognition and exposure to HIV prevention interventions, including the national mass-media prevention campaign, campaign logos, and campaign audio recordings are presented to participants, along with control HIV/STI prevention logos and audio recordings. Participants are asked which logos they had previously seen and which audio recordings they had previously heard. Those surveyed are also asked about their health-seeking behaviour and the frequency with which they utilised public health centres.

Data are entered in a database, cleaned and analysed using the statistical software STATA. A summary of the results is presented to the Public Health Commissioner of Great Gorge.

Although the study cannot afford to provide HIV or STI testing, referrals and vouchers for these services are offered to all street children who participate in the survey.

Part 6. Results, continued

The survey produces the following results:

Demographics

- The sample included 600 street children (480 boys and 120 girls).
- Median age of those who participated was 16 years (range 12–19).
- Boys were significantly older than girls (median age 17 vs. 14, $p<.01$).
- Girls were more likely in contact with their families than boys ($p<.05$).
- Most respondents lived on the street or in illegal squatter settlements.
- Only 6% (36) of respondents had electricity at the location where they spent the last night.
- Forty-five percent (267) of respondents were literate (50% of boys; 22.5% of girls).
- Five percent of those surveyed reported having run away from home as a result of sexual or physical abuse in their home (with girls more frequently reporting this occurrence, $p<0.05$).
- Fifteen percent reported growing up on the street as a result of being born out of wedlock.
- Ten reported having run away from home because of a forced marriage (girls more frequently reported this occurrence, $p<0.05$).

Sexual behaviours

- A significantly higher proportion of boys (67%) than girls (30%) reported ever having had sexual intercourse ($p<.01$).
- Median age of sexual debut was 15 for boys and 13 for girls.
- Fifteen percent of female respondents reported having performed sex or sexual favours for money within the previous year, compared to only 4% of male respondents.
- An additional 10% of female respondents reported having exchanged sex for food or other goods, mostly with other street children.
- Five percent of male respondents reported having provided female street children with food or protection in exchange for sex or sexual favours.
- Eleven percent of female respondents reported having been raped while living on the streets.
- Twenty-six percent of those who were sexually active reported history of condom use “in general,” while 72% reported using a condom during most recent sexual intercourse.

Part 6. Results, continued

Drug use

- Hashish was the substance most frequently used within the year among boys (85%) and girls (79%).
- Girls were less likely than boys to report having used hashish, marijuana, inhalants and/or methamphetamines in the last year ($p<.05$).
- Injection drug use was reported by 15% of participants, all male.

HIV knowledge

- Nearly all respondents had heard about HIV/AIDS, but only 32% mentioned that consistent use of condoms could prevent transmission of HIV and other STIs.
- Fifty-six percent of respondents believed that they would never get HIV.
- Eleven percent of the participants reported having been tested for HIV; only one respondent reported that he/she was HIV-infected.

Exposure to interventions

- Only 12% of those surveyed had been exposed to the government's mass-media HIV prevention campaign.
- All those who had been exposed to it had heard the radio component of the campaign.
- Nearly all of the youth surveyed knew the locations of the public health centre that served street children, yet only 10% reported having utilised these services.
- Fear of being arrested or "sent home" was the most commonly cited reason why street children did not utilise public health services.

1. Based on the community survey, what are the main factors that put street children at risk of transmitting and acquiring HIV?

2. What interventions should be initiated based on these results?

Part 7. Epilogue

Based on the community survey, street children were highly at risk of acquiring and transmitting HIV; HIV-related knowledge was low, many female street children had performed sex work and had been raped or abused, and many children had run away from home to escape abusive relationships or forced marriages. Injection drug use was alarmingly high, although glue sniffing and smoking hashish were also common. Street children surveyed did not utilise the public health centres, although they knew the centres existed. Urgent targeted interventions were needed to increase safe sex practises and HIV-knowledge among street children in Great Gorge.

Based on these findings, the public health commissioner of Great Gorge directs the HIV programme manager to initiate the following interventions:

- Design interventions specifically targeted at street children.
- Engage peers and NGO outreach workers to educate street children about HIV/STI transmission and prevention.
- Disseminate "best practises" to researchers and practitioners who have worked with street children across different cities.
- Work with local police and public health centres to establish times when street children can visit public health centres without fear of being arrested or persecuted.

Unit 7

Prisoners

Overview

What this unit is about

This unit describes the background and special ethical considerations associated with conducting HIV surveillance in populations of prisoners. It presents sampling options and recommends specific surveillance methods for this group.

Warm-up questions

1. Which of the following is a reason for high HIV prevalence among prisoners?

   a. the over-representation of injecting drug users among prisoners
   b. male-to-male sex during long periods of incarceration
   c. sexual relations between prison staff and prisoners
   d. high concentration of female sex workers in some prisons
   e. the sharing of needles for drug use in prison
   f. all of the above

2. True or false? The most practical way to collect information on HIV prevalence in prisons is to use the mandatory screening programmes when prisoners are admitted.

   True False

3. What is the simplest form of sampling that can be used if you are surveying prisoners who are already incarcerated?

   a. cluster sampling
   b. systematic random sampling
   c. snowball sampling
   d. time-location sampling

Warm-up questions, continued

4. True or false? High HIV prevalence among prisoners is a result of HIV infection both before and after entering the criminal justice system.

   True False

5. Cohort studies provide the most exact measurements of incidence, but they require the studied groups to be relatively stationary. Which of the following groups can be surveyed using cohort studies?

   a. street-based sex workers
   b. migrant workers
   c. prisoners
   d. refugees

6. Because of their inability to give true voluntary _____, prisoners are a vulnerable population and need special ethical protection.

Introduction

What you will learn

By the end of this unit, you should be able to:

- understand the factors that contribute to the high prevalence of HIV among prisoners
- describe options for sampling and surveillance methods within prison populations
- describe the special ethical and legal considerations associated with surveillance in prisoner populations.

Background

Definition

Both male and female prisoners are at a higher risk for HIV infection. For the purpose of this unit, we define a *prisoner* as any person involuntarily confined or detained in a penal institution, including persons detained pending arraignment, trial, or sentencing. We use the term "prison" broadly for any place of detention, including:

- reform centres
- police stations and jails
- centres for pre-trial and convicted prisoners
- centres for juvenile offenders
- centres for refugees, illegal immigrants and/or asylum seekers
- mandatory re-education and rehabilitation centres, such as those for *injecting drug users* (IDUs).

Role of prisoners in the HIV epidemic

Prison settings have contributed to the rapid spread of HIV infections. There are multiple and powerful factors contributing to the high *prevalence* of HIV in prisons, including:

- the high concentration of arrested IDUs and *sex workers* (SWs)
- consensual and non-consensual male-to-male sex, especially during long periods of incarceration
- syringe sharing with multiple injectors
- tattooing with unsafe needles. This factor is theoretical, although it is clearly a risk for *hepatitis B virus* (HBV) and *hepatitis C virus* (HCV) infection.

Furthermore, HIV prevention measures are uncommon in prisons. A small but increasing number of countries provide methadone maintenance

Role of prisoners in the HIV epidemic, continued

programmes, needle and syringe programmes, or condoms to prisoners (Dolan K et al., HIV in prison in low-income and middle –income countries. Lancet Infectious Disease 2007;7:32-41). Since 1996, for example, South Africa is the only African country providing condoms and lubricant to prisoners upon request.[2] Additionally, although injectable drugs, such as heroin, are illegally available in some facilities, access to sterile injection equipment is limited.

Female prisoners often are incarcerated for sex work and therefore can have a higher prevalence of HIV than do male prisoners. Additionally, sexual relations between correctional staff and female prisoners may contribute to the high prevalence of HIV among female prisoners.

Prevalence of HIV among prisoners

Levels of HIV *sero-prevalence* have become alarming in many prison populations around the world. The high HIV prevalence levels in prisoners are the result of both the high rates of HIV infection before persons enter prison and the high transmission rates within prisons. Transmission within prisons is likely the result of both high-risk sex and the sharing of needles for injection drug use.

Although HIV transmission among prisoners has been reported in some countries, the infrequency of these reports has led to the belief that HIV transmission rarely occurs among prisoners. A more likely explanation for the lack of these reports is that sero-prevalence studies are more difficult to conduct in prisons than in community settings, due to the difficulty of gaining access to prison populations.

The prevalence of HIV infection among prisoners varies by country and region. Consider the following examples:

- Nationally in South Africa and Zambia, HIV prevalence among prisoners was found to be 43.5% and 27%, respectively (Dolan K et al., HIV in prison in low-income and middle –income countries. Lancet Infectious Disease 2007;7:32-41).
- There is a need to expand outreach programmes to provide comprehensive harm reduction services to IDUs, even in the prisons. Among prison inmates in one Bangkok prison, HIV prevalence was 25% (Thaisri et al., 2003, UNAIDS).

[2] Senok A, Botta G. Human immunodeficiency virus and hepatitis virus infection in correctional institutions in Africa: is this the neglected source of the epidemic? Editorial. 2006. Journal of Medical Microbiology.

Prevalence of HIV among prisoners, continued

- A study in Belize central prison showed HIV prevalence of 5% among prisoners (Ministry of Health Belize, 2005, UNAIDS). CARIBBEAN
- In the Russian Federation, nationally, HIV prevalence among prisoners reached an estimated 4.3% in 2006 (Ladnaya, 2007, UNAIDS).
- Among 764 prisoners tested in Kuwait in 1999, 4 (<1%) tested positive for HIV.
- One study found an HIV prevalence of 18% among prisoners in Libya (Sammud A, 2005)
- Almost 6% of male inmates tested at a Sao Paulo, Brazil, penitentiary were found to be HIV-positive (Coelho et al., 2007), as were 14% of the women at a detention facility in the same city (Strazza et al., 2007). UNAIDS.
- In studies from Khudzhand and Dushanbe (2005), Tajikistan, the HIV prevalence among inmates was 6%-7% (www.euro.who.int/aids/ctryinfo/overview/20060118_44).

Bridges and overlap with other populations

Prison populations are fluid, with movements of prisoners, prison staff, and visitors. Prisoners also overlap with other high-risk groups, including IDUs and SWs. Due to the illegal nature of sex work and injecting drug use, SWs and IDUs may be concentrated in prisons and jails.

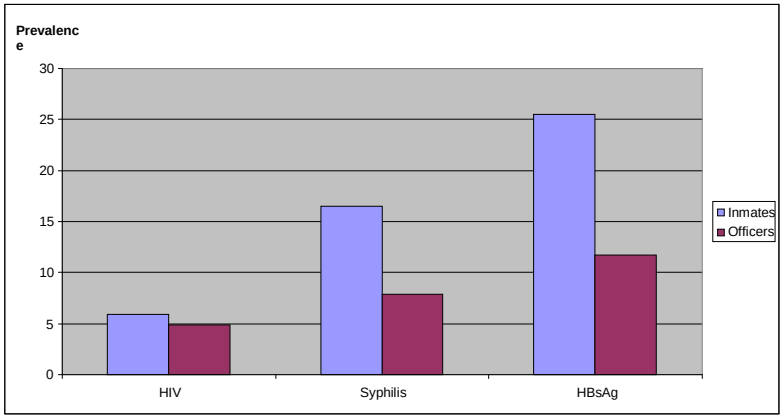
Also, upon release, prisoners may transmit HIV acquired during their incarceration to others, acting as a *bridge* between a high-risk group and the general population. Failure to address the HIV transmission that occurs in prisons may undermine the success of HIV prevention programmes targeted at the *general population*.

An example

In Bangkok, Thailand, an HIV outbreak occurred in December 1987 when a prison amnesty was declared for the King's birthday. Many prisoners were released, including some who were HIV positive or IDUs, instigating an outbreak from the ex-prisoners to their injecting and sex partners. The prevalence of HIV among IDUs attending drug treatment rose from 2% in January 1988, to 27% in March 1988 (Dolan K et al., HIV in prison in low-income and middle-income countries. Lancet Infectious Disease 2007;7:32-41).

A national, multi-centre, cross-sectional study in Ghana was undertaken to provide behavioural and sero-prevalence information about prison inmates and officers. The following figure (Figure 7.1) and table (Table 7.1), on the next page, describe the results:

Figure 7.1. Sero-prevalence among prison inmates and officers in Ghana (2007)



Source: Adjei et al., Correlates of HIV, HBV, HCV and syphilis infections among prison inmates and officers in Ghana: a national multicenter study. BMC Infectious Diseases 2008, 8:33.

Table 7.1. Independent determinants for HIV, HBV, and syphilis infections among prison inmates and officers

Prison inmates	Officers
▪ Aged between 17 and 46 ▪ Unmarried ▪ Illiterate ▪ Female ▪ Incarcerated longer than 36 months ▪ History of homosexuality ▪ History of being an IDU ▪ History of sharing syringes and drug paraphernalia ▪ History of sex work ▪ History of having a *sexually transmitted infection* (STI)	▪ Aged between 25 and 46 ▪ Female ▪ Unmarried ▪ Employed in prison service longer than 10 years ▪ History of having an STI

Source: Adjei et al., Correlates of HIV, HBV, HCV and syphilis infections among prison inmates and officers in Ghana: a national multicenter study. BMC Infectious Diseases 2008, 8:33.

Conducting a Formative Assessment

Building alliances

As access to prisoners is regulated, you must obtain permission from governmental authorities and/or prison administrators before conducting any *surveillance* activities.

Building *alliances* with the community *networks* involved with prisoners, including the Ministry of Justice, prison administration and staff, and healthcare workers at prisons will help you design and conduct surveillance activities and do your *formative assessment*. Prison wardens are important *gatekeepers* who can provide access to prisoners.

Formative assessment questions

Conducting a formative assessment will help you identify important *indicators* to measure the diversity of the sub-populations of prisoners and the structure and procedures of prisons for surveillance purposes. Information gathered during your formative assessment will help you answer the following questions:

- What are the different types of facilities for incarceration in your country: city, sub-national and national-level jails, prisons and penitentiaries?
- What are your country's policies for testing prisoners for HIV at each level?
- Are HIV-infected prisoners kept at separate facilities?
- Are prisoners routinely screened on admission or at some other time during incarceration?
- Are surveys of currently incarcerated prisoners practical and ethical?
- Are surveys of prisoners at the time of or immediately following release feasible?

Other organisations or individuals may also be helpful, such as:

- persons from the Ministry of Interior
- persons from the Ministry of Justice
- prison wardens and correctional officers
- human rights organisations
- prisoner rights organisations
- *Non-governmental organizations* (NGOs) that provide social services programmes for prisoners.

Selecting a Sampling Method

Some countries have mandatory HIV testing for prisoners upon entry. If all persons entering prison undergo mandatory screening for HIV and the data are available to surveillance staff, *sampling* is not necessary.

In counties where mandatory HIV testing is not standard and for more complex surveys, such as surveys of prisoners who are currently incarcerated or surveys of prisoners at the time of release, some form of random sampling may be appropriate. One approach, for example, is to conduct combined *biological surveillance* and *behavioural surveillance* on a consecutive or systematic sample of prisoners after their intake or at an initial health assessment. As with all surveillance activities, surveillance must be regular and ongoing to be effective.

Information gathered during your formative assessment will guide you in selecting sampling approaches that are appropriate and practical.

As the prevalence of HIV, STIs, and *risk behaviour* varies between facilities, it is important to keep in mind that results of a study conducted in a particular facility may not be generalizable to the entire prisoner population of a country.

Measures and Indicators

Ideally, sero-prevalence studies should be combined with behavioural surveillance. This will allow you to understand the behaviours that affect the prevalence of HIV, STIs and *parenterally transmitted* infections.

Surveys that collect behavioural and biological information on HIV, STIs, and risk behaviours should include *informed consent*. The focus of the questions may vary based on gender, as summarised in Table 7.2.

Table 7.2. Focus of behavioural surveillance, by prisoner gender.

Prisoner gender	Focus of surveillance
Male	1. injection drug use before and during incarceration 2. male-to-male sex in prison 3. heterosexual sex before incarceration
Female	4. injection drug use before and during incarceration 5. heterosexual sex before and during incarceration

Discussing the table

Looking at Table 7.2, answer the following questions:

a. What focuses of surveillance are common to both male and female prisoners?

b. In which group is heterosexual sex during incarceration more important?

Biological measures

Measuring HIV sero-prevalence among prisoners is a possible component of surveillance. The high sexual risk among prisoners also makes STI testing a useful and feasible indicator for surveillance. For information on the available STI and HIV tests, refer to the WHO test kit evaluation programme: http://www.who.int/diagnostics_laboratory/evaluations/en/

Biological measures, continued

Because prisoners may have injected drugs prior to or during their incarceration, laboratory tests for HCV may be a useful biological measure.

Possible biological measures to include when conducting surveillance among prisoners are presented in Table 7.3.

Table 7.3. Possible biological measures.

Biological Measure	Notes
Syphilis	*Syphilis* testing is often the most efficient biological indicator, because the standard tests can be done with the same serological specimen as with the HIV testing. The test is relatively inexpensive and widely available.
Gonorrhoea	Accurate tests for *gonorrhoea* are expensive and usually require a urine specimen.
Chlamydia	Accurate tests for *Chlamydia* are expensive and usually require a urine specimen.
Herpes simplex virus type 2	*HSV-2* testing is a marker for lifetime sexual risk. However, it is less readily available. To be an indicator for sexual risk, the test needs to distinguish HSV-2 from *HSV-1*.
Hepatitis C virus (HCV)	HCV is a good marker for injection drug use.

In rare cases, and where permitted by law, urine specimens may also be tested for the presence of opiates and methamphetamines.

Behavioural measures

Behavioural measures should focus on sexual and parenteral risk behaviours. Because SWs and IDUs may be present in high numbers in jails and prisons, measures used in community-based surveys of these populations may be appropriate when conducting behavioural surveillance among prisoners. Further information on the behavioural measures used in surveys of SWs and IDUs are discussed in Unit 2: Sex Workers and Unit 3: Injecting Drug Users.

Standard or basic indicators that assess HIV risk among prisoners include:

- having received HIV testing in the last 12 months and knowing the results (*United Nations General Assembly Special Session on HIV/AIDS* [UNGASS])
- correctly identifying ways of preventing the sexual transmission of HIV and rejecting major misconceptions about HIV transmission (UNGASS).

These basic indicators may be supplemented with local measures of particular importance in your area, as determined by your formative assessment phase. These additional indicators may include:

- reason for incarceration
- drug use, injection and non-injection
- marital status
- occupation before incarceration
- term of sentence in years or months
- history of attending a drug abuse treatment clinic.

Reference to indicators

Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found in Unit 1.

Indicators recommended by international bodies will not necessarily capture all behaviours relevant to your area. Some questions will be for local use only (for example, exposure to specific prevention programmes or assessing particular risk practises). The formative assessment phase should be used to determine the local questions of greatest relevance to the epidemic in your area. In addition, the wording of the indicators will have to be translated and field-tested in your local languages.

Estimating incidence

Because prisoners are a relatively stationary group, calculating the *incidence* of HIV in prisons may be possible. Cohort studies provide the most exact measurements of incidence, but are only possible if correctional staff members allow public health workers access to prisoners for HIV testing during their incarceration. A few studies have surveyed prisoners as they are released and calculated the incidence of HIV in prisons. Additionally, recidivists (persons who are repeatedly arrested for criminal behaviour) form dynamic cohorts for HIV incidence studies. Ideally, incidence studies should be combined with behavioural surveillance to aid in understanding the specific risk behaviours contributing to HIV incidence.

Tuberculosis testing

The prevalence of *tuberculosis* (TB) is up to 100 times higher in prisons than in the general population. HIV/TB co-infected persons are more likely to progress to active TB disease than are persons infected with TB alone. Additionally, studies have shown that infection with TB enhances replication of HIV and may accelerate the progression of HIV infection to AIDS.

If you suspect high rates of HIV/TB co-infection among prisoners in your country, you should consider entrance-point tuberculin skin testing or chest x-ray of prisoners and periodic testing of prisoners and prison staff. This testing is done for clinical purposes, to identify and treat individuals with latent and active TB and to control TB transmission in prisons. Results from these surveys also can be used for TB prevalence estimates.

Special Ethical Considerations

Conducting HIV surveillance among prisoners raises a number of ethical and legal issues.

Special protections for persons who are the subjects of biomedical and behavioural research are listed in the Helsinki Declaration, issued by the World Medical Association. This document is available at www.wma.net/e/policy/b3.htm. The Helsinki Declaration states:

> Medical research is subject to ethical standards that promote respect for all human beings and protect their health and rights. The particular needs of the economically and medically disadvantaged must be recognised. Special attention is also required for those who cannot give or refuse consent for themselves, for those who may be subject to giving consent under duress, for those who will not benefit personally from the research and for those for whom the research is combined with care.

As prisoners are unable to give true voluntary informed consent, they are a *vulnerable population* and need special ethical protection.

Because of their unique situation, special efforts are required to ensure the privacy, rights, and safety of prisoners participating in HIV testing, the provision of adequate care if they are found to be infected, and the safety and security of the staff conducting the study. Most prevalence studies require that the investigators alert the potential study participants to the possible consequences, legal or otherwise, of admitting drug use or having sex in prison. Furthermore, some *institutional review boards* (IRBs) require the input of a prisoner advocate.

Informed consent

Informed consent is required when conducting prevalence studies and other activities involving the non-routine collection of data. In every area of life, prisoners bargain for privileges and better conditions. Because of their incarceration, prisoners are under unique constraints that affect their ability to make a truly voluntary and un-coerced decision about whether to participate as research subjects. For this reason, many countries have prohibited all research involving prisoners. In settings where research involving prisoners is allowed, it is important to take special precautions when obtaining informed consent from prisoners.

Assuring confidentiality

Confidentiality protects subjects from the negative consequences that may arise from participating in a study or survey. The confidentiality of medical information in the prison setting is virtually impossible to maintain.

Prisoners asked to participate in surveillance activities should understand potential threats to their confidentiality. They should also understand the steps that the investigators will take to minimise these threats. Explaining these issues to them is part of the informed consent process.

Steps you can take to minimise threats to confidentiality may include:

- conducting interviews with prisoners in private settings
- keeping the names of the prisoners separate from the data collected about them
- limiting access to any identifying information to authorised study personnel only
- keeping study documents in a locked, limited-access room
- having all staff sign confidentiality forms and undergo training in research ethics.

Some correctional facilities isolate HIV-infected prisoners from the general prison population. In settings where HIV-infected prisoners are kept in separate facilities or areas from uninfected prisoners, ensuring confidentiality is not possible.

If the correction facility has isolation for HIV-infected prisoners, then:

- prisoners must be informed about the treatment options available in the facility
- prisoners must be made aware of who has access to their medical records
- prisoners' rights must be considered by IRBs.

Summary

Multiple factors contribute to the high prevalence of HIV in prisons, including the high rates of HIV infection before entering prison and HIV transmission within prisons. Because sex work and injection drug use are illegal in many countries, large numbers of these MARPs may be present in prisons.

Special ethical considerations must be made when conducting surveillance activities among prisoners. Ethically, prisoners are considered a special population due to their possible inability to give true informed consent. The sampling method best suited for sampling prisoners in your area will depend largely on your country's policies regarding mandatory HIV testing. Behavioural and biological measures to include when conducting HIV surveillance among prisoners should focus on the markers of sexual and injecting risk behaviours.

NOTES

Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of this unit. Make any changes you want to.

Small group discussion

Get into small groups to discuss these questions.

1. Does your country conduct behavioural and/or sero-surveillance of prisoners?

2. In your country, who are the gatekeepers of this population?

3. In your country, what methods have been used to sample prisoners?

4. In your country, what behavioural and biological measures have been used when conducting surveillance of prisoners?

5. In the past five years, has the prevalence of HIV among prisoners increased, decreased, or remained about the same?

Apply what you have learned/ case study (1)

Biological and behavioural surveillance of prisoners at Central Prison, Globa

Part 1: Introduction

Central Prison is the largest adult male correctional facility in Globa and houses prisoners from all regions of the country. The HIV surveillance team of the National AIDS Control Programme (NACP) recently received a report from an NGO that found previous incarceration to be one of the strongest predictors of HIV infection among males in Globa. The NACP is concerned that released prisoners are a potential source of HIV transmission to the general population.

The surveillance team, in collaboration with the Ministry of Justice, decide to conduct a sero-prevalence assessment of prisoners at the Central Prison. It is estimated that approximately 50% of all prisoners are incarcerated on drug-related offences. The minimum stay for the prison is 12 months; persons sentenced to less time are held in local jails.

Previous studies showed an HIV prevalence of 5% among the prisoners tested. Biological data suggest that persons entering prison had engaged in risky sexual and injecting behaviours prior to their incarceration. To determine whether this is true, the HIV surveillance team decide to investigate the details.

- What are the possible approaches to conducting a behavioural survey among prisoners at Central Prison?
- What are some of the ethical issues you must consider prior to conducting a behavioural survey in a prison population?
- What behavioural variables should be collected?

Part 2: Collecting behavioural data

After carefully considering the pros and cons of various sampling approaches, the HIV surveillance team decide to conduct a detailed behavioural survey to assess the pre-incarceration sexual and injecting behaviour of 700 prisoners. Although blood and urine are routinely collected at intake, behavioural data are not routinely collected. In addition, the team wish to do follow-up HIV testing to measure HIV incidence in the prison.

Informed consent is required before prisoners can participate in this study. Some of the ethical issues facing the HIV surveillance team are:

- the inability of prisoners to give true informed consent
- issues surrounding confidentiality
- issues around giving incentives for participating.

The HIV surveillance team approach the first 700 male prisoners who arrived at Central Prison between January and April 2007 and explain the purpose of the behavioural survey. After receiving assurance that confidentiality will be maintained, 525 prisoners provide informed consent and agree to participate in the survey. The HIV surveillance team administer a baseline questionnaire that includes the following variables:

- socio-demographic information:
  - age
  - marital status
  - occupation prior to incarceration
  - monthly income
  - residence prior to incarceration

- arrest/incarceration information:
  - type of offence and whether drug related
  - duration of sentence
  - past history of incarceration

- injecting behaviour:
  - which drugs
  - sharing of injection equipment

- sexual behaviour:
  - sex with steady and casual partners
  - sex with SWs
  - sex with other men
  - condom use

Part 2: Collecting behavioural data, continued

Researchers find that the behavioural data support the biological data:

- Nearly 50% of respondents are incarcerated on drug-related charges.
- Thirty-eight percent of respondents injected prior to incarceration.
- Heroin was the most commonly injected drug.
- Twenty-two percent reported having shared injection equipment, such as needles and syringes, in the month prior to their incarceration.
- Three percent reported sex with men before incarceration
- Many have a history of prior incarceration.

Although the survey data suggest that many inmates engaged in high-risk behaviour prior to their incarceration, engaging in high-risk behaviours within the prison is also prevalent. The HIV surveillance team decide to assess the incidence of HIV inside Central Prison.

1. Describe how the HIV surveillance team could measure HIV incidence among Central Prison inmates.

2. What behaviours could explain the increase in HIV among the prisoners?

Part 3: Estimating incidence

To determine the incidence of HIV during incarceration in Central Prison and the behaviours related to infection, the HIV surveillance team follow 500 HIV-uninfected prisoners for 12 months. After 12 months, these prisoners are re-tested for HIV and their in-prison risk behaviours are assessed.

Behavioural data from follow-up surveys produce the following results:

- Fifteen percent (75/500) inject heroin while in prison, all of which report sharing needles and other injection equipment due to the unavailability of sterile injecting equipment.
- Five percent (25/500) inject heroin, share injecting equipment, and engage in unprotected male-male sex while in prison.
- Five percent (25/500) do not inject heroin but do engage in unprotected male-male sex while in prison.
- Four percent (20/500) sero-converted in the 12-month period.
    - Eighteen reported injecting while in prison (HIV incidence among injectors 24% per year).
    - Two reported male-male sex but no injecting (HIV incidence among those reporting male-male sex but no injection 8% per year).

The HIV surveillance team conclude that many prisoners who are uninfected when they enter Central Prison are contracting the virus while incarcerated through sharing of injection equipment with HIV-infected prisoners and, to a lesser extent, through unprotected male-male sex.

1. What interventions should be initiated based on these results?

Part 4: Epilogue

Based on these findings, the NACP directs the Ministry of Justice to increase the funding for prison-based drug treatment programmes and HIV interventions. The NACP directs the Ministry of Justice to consider the following options and consider the practicality of implementing them:

- provide prison-based HIV education
- initiate antiretroviral therapy for prisoners according to national guidelines
- establish drug treatment and methadone programmes for prisoners who are IDUs
- establish condom programmes within the prisons
- distribute sterile injecting equipment to prisoners.

Apply what you have learned/ case study (2)

Biological and behavioural surveillance of prisoners at Muri City Central Prison, Natan Island

Part 1: Mandatory HIV testing

Muri City, a city with a total population of 12 million, is the capital of Natan Island, an island nation in Southeast Asia. The HIV surveillance team of the National AIDS Control Programme (NACP) recently received a report from an NGO that found previous incarceration to be the strongest predictor of HIV infection among males in Muri City. The NGO is concerned that prisoners released are a potential source of HIV infection to the community.

The surveillance team, in collaboration with the Ministry of Justice, decide to conduct a sero-prevalence assessment of prisoners at Muri City Central Prison. Muri City Central Prison is the largest adult male correctional facility in Natan Island and houses prisoners from all regions of Natan Island. It is estimated that approximately 50% of all prisoners are incarcerated on drug-related offences. The minimum stay for the prison is 12 months; persons sentenced to less time are held in local jails.

Recently, the prison began HIV, STI, HCV, and drug testing of all prisoners upon arrival. A routine physical is performed and blood and urine samples are collected from all newly arriving prisoners. Blood samples are tested for HIV, HCV, and syphilis, and urine samples are tested for Chlamydia, opiates, and methamphetamines.

Because all new prisoners are screened for HIV, STIs, and HCV at intake, the HIV surveillance team decide to analyse data from all prisoners arriving at the prison between January and June 2006.

Part 1: Mandatory HIV Testing, continued

A total of 700 adult male prisoners are included in the sample and produce the following biological results:

- 77 (11%) prisoners test positive for Chlamydia
- 35 (5%) are HIV-infected
- 21 (3%) are reactive for syphilis
- 189 (27%) are reactive for HSV-2
- 84 (12%) are reactive for HCV.
- 385 (55%) test positive for opiates
- 70 (10%) test positive for methamphetamines.

Biological data suggest that persons entering prison engaged in risky sexual and injecting behaviours prior to their incarceration. To determine whether this is true, the HIV surveillance team decide to investigate the details of sexual and injecting risk behaviour of these prisoners prior to their incarceration.

1. What are the possible approaches to conducting a behavioural survey among prisoners at Muri City Central Prison?

2. What are some of the ethical issues you must consider prior to conducting a behavioural survey in a prison population?

3. What behavioural variables should be collected?

Part 2: Collecting behavioural data

After carefully considering the pros and cons of various sampling approaches, the HIV surveillance team decide to conduct a detailed behavioural survey to assess the 700 prisoners' pre-incarceration sexual and injecting behaviour. Although blood and urine are routinely collected at intake, behavioural data are not routinely collected. In additional, they wish to do follow-up HIV testing to measure HIV incidence in the prison.

Informed consent is required before prisoners can participate in this study. Some of the ethical issues facing the HIV surveillance team are:

- the inability of prisoners to give true informed consent
- issues surrounding confidentiality
- issues around giving incentives for participating.

The HIV surveillance team approach the 700 male prisoners (35 of whom tested positive for HIV) who arrived at Muri City Central Prison between January and April 2006 and explain the purpose of the behavioural survey. After receiving assurance that confidentiality will be maintained, 525 prisoners (25 of whom are HIV-infected and 500 of whom are HIV-uninfected) provide informed consent and agree to participate in the survey. The HIV surveillance team administer a baseline questionnaire that includes the following variables:

- socio-demographic information:
  - age
  - marital status
  - occupation prior to incarceration
  - monthly income
  - residence prior to incarceration

- arrest/incarceration information:
  - type of offence (drug-related or not)
  - duration of sentence
  - past history of incarceration

- injecting behaviour:
  - which drugs
  - sharing of injection equipment

- sexual behaviour:
  - sex with steady and casual partners
  - sex with sex workers
  - sex with other men
  - condom use

Part 2: Collecting behavioural data, continued

Researchers find that the behavioural data support the biological data.

- Nearly 50% of respondents are incarcerated on drug-related charges
- 38% of respondents injected prior to incarceration
- Heroin was the most commonly injected drug
- 22% reported having shared injection equipment (such as needles, syringes) in the month prior to their incarceration
- Most respondents (82%) reported having visited female SWs in the year prior to their incarceration
- 95% reported unprotected sex in the past year
- 6% reported sex with men before incarceration
- 80% of the HIV-positive inmates have a history of previous incarceration, compared to 30% of HIV-negative inmates.

Although the survey data suggest that many inmates could have been infected during previous incarcerations, risk behaviours outside of prison are also high. The HIV surveillance team decide to assess the incidence of HIV inside Muri City Central Prison.

1. Describe how the HIV surveillance team could measure HIV incidence among Muri City Central Prison inmates.

2. What behaviours could explain the increase in HIV among the prisoners?

Part 3: Estimating incidence

To determine the incidence of HIV during incarceration in the Muri City Central Prison and the behaviours related to infection, the HIV surveillance team follow the 500 HIV-uninfected prisoners and the 25 HIV-infected prisoners for 12 months. After 12 months, the 500 uninfected prisoners are re-tested for HIV and their in-prison risk behaviours are assessed. The in-prison risk behaviours of the 25 HIV-infected prisoners are also assessed.

Behavioural data from follow-up surveys produce the following results:

Of the 25 HIV-infected prisoners:

- 72% (18/25) inject heroin while in prison, all 18 reported sharing needles and other injection equipment.
- 28% (5/18) of the men who injected heroin in prison also engaged in unprotected male-male sex while in prison.

Of the 500 HIV-uninfected prisoners:

- 15% (75/500) inject heroin while in prison, and all of this percentage report sharing needles and other injection equipment due to the unavailability of sterile injecting equipment.
- 5% (25/500) inject heroin, share injecting equipment and engage in unprotected male-male sex while in prison.
- 5% (25/500) do not inject heroin but do engage in unprotected male-male sex while in prison.
- 4% (20/500) sero-converted in the 12-month period.
    - 18 reported injecting while in prison (HIV incidence among injectors 24% per year)
    - Two reported male-male sex but no injecting (HIV incidence among those reporting male-male sex but no injection 8% per year)

The HIV surveillance team conclude that many prisoners who are uninfected when they enter Muri City Central prison are contracting the virus while incarcerated through sharing of injection equipment with HIV-infected injectors and, to a lesser extent, through unprotected male-male sex.

1. What interventions should be initiated based on these results?

Part 4: Epilogue

Based on these findings, the National AIDS Control Programme directs the Ministry of Justice to increase the funding for prison-based drug treatment programmes and HIV interventions. The NACP directs the Ministry of Justice to consider the following options and consider the feasibility of implementing them:

- to establish drug treatment and methadone programmes for IDU prisoners
- to provide prison-based HIV education;
- to initiate anti-retroviral therapy for prisoners with HIV clinical stages 3 and 4.

Unit 8
Uniformed Personnel

Overview

What this unit is about

This unit describes the background and special considerations associated with conducting behavioural and HIV sero-surveillance among uniformed personnel, such as police and members of the military. It explains sampling and surveillance methods and recommends specific surveillance methods for this group.

Warm-up questions

1. List three reasons why uniformed personnel are at increased risk of HIV infection.

   a.

   b.

   c.

2. Access to uniformed personnel is usually restricted. Military officials, such as senior commanders and medical officers, are important _____ who can provide access to uniformed personnel.

3. _____ is required when conducting prevalence studies and other activities involving the non-routine collection of data.

4. List two methods that may be used for sampling uniformed personnel.

   a.

   b.

Introduction

What you will learn

By the end of this unit, you should be able to:

- describe the special considerations associated with surveillance of uniformed personnel
- describe options for sampling and surveillance methods among uniformed personnel.

Background

Definitions

Uniformed personnel may include members of the armed services, police forces, border guards, guards at correctional facilities, and other law enforcement officers.

Role of uniformed personnel in the HIV epidemic

Throughout the world, uniformed personnel are often at especially high risk for HIV and AIDS. In many countries, HIV *prevalence* is much higher among uniformed personnel than it is in the *general population*.

Uniformed personnel are at increased risk of acquiring HIV because they are:

- usually young and sexually active
- often away from home
- susceptible to peer pressure
- inclined to feel invincible and to take risks
- surrounded by opportunities for casual sex
- in possession of disposable income or have access to material resources
- frequently the clients of female *sex workers* (SWs)
- high prevalence of *sexually transmitted infections* (STIs).

Role of uniformed personnel in the HIV epidemic, continued

Furthermore, deployment to conflict areas increases their chances of acquiring HIV due to:

- the possibility of infection through exposure to traumatic injuries, requiring transfusion of HIV-infected blood
- the frequent absence of adequate HIV testing and monitoring equipment in conflict areas.

It has been well documented that the presence of STIs increases the risk of transmitting and acquiring HIV infection. Peacetime STI infection rates in military personnel are two to five times higher than in the civilian population.

HIV prevalence among uniformed personnel

The prevalence of HIV among uniformed personnel varies by country and region. As access to uniformed personnel usually is restricted, data on the prevalence of HIV among this population is scarce in many countries.

Consider the following examples:

- According to UNAIDS, in Cambodia, 12% to 17% of the armed forces were estimated to be HIV-infected in 1999, compared with 3.7% among the general population (Strong Fighting: Sexual Behavior and HIV/AIDS in the Cambodian Uniformed Services. Ian Ramage, for FHI, 2002.).
- In India, AIDS is the fifth leading medical reason for being "invalided" out of the army and the second most common cause of death in the navy.[3]
- In Cambodia, among policemen, HIV prevalence fell from 4.5% in 1997 to 2.7% in 2003—resulting from a combination of mortality and significant behaviour change (UNAIDS).
- A November 2003 *sero-prevalence* survey among army personnel in Angola found the highest HIV prevalence (11%) near the border with Namibia, with substantially lower prevalence in other parts of the country, 5% in Luanda and less than 3% in the remote areas of Kuito and Dundo, consistent with the results of sero-prevalence surveys among women attending antenatal clinics. (Department of Defense HIV/AIDS prevention Program Status Report. Angola, May 2003-September 2004, http://www.nhrc.navy.mil/programs/dhapp).

[3] Singh, M., Armed Forces of India AIDS Control Programme, presentation at Asia Pacific Military Medicine Conference XIII, Bangkok, 11-16 May 2003.

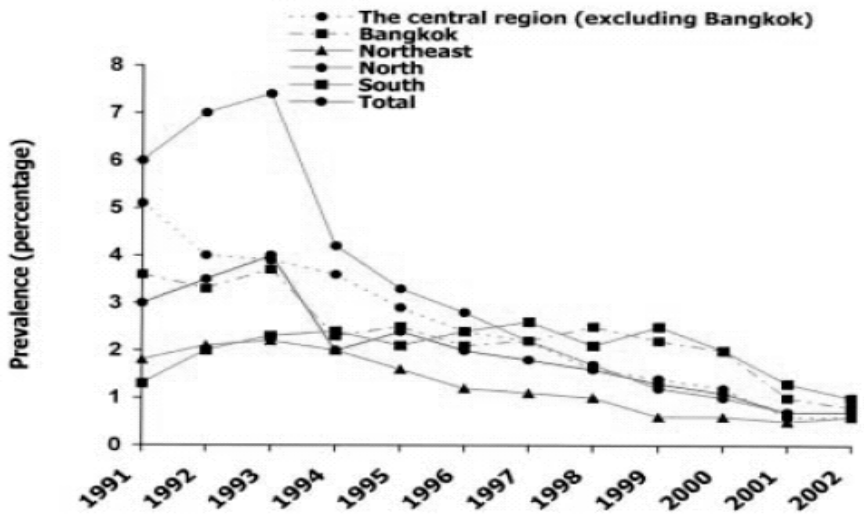
- In Ethiopia in 1996, sailors were found to have an HIV-1 prevalence of 9.6%. The risk of acquiring infection was found to increase with the use of hypodermic injections (OR=3.42, 95% CI: 1.19-9.80).[4]
- The US Bureau of the Census maintains the HIV/AIDS Surveillance Data Base. Its Population Division took data from Latin American and Caribbean countries to describe the levels and trends of HIV infection as they apply to geography, time, and population. In 1995, they found the HIV sero-prevalence rate among the military was 0.8% in Buenos Aires, Argentina, and 0.4% in El Salvador and Guatemala.[5]
- Sero-prevalence data regarding the Sudanese military are limited, but an ongoing survey has found greater levels of HIV among soldiers near the Ugandan border, while rates in the interior are consistent with those in civilian communities. (UNAIDS 2005. On the front line: A review of policies and programmes to address AIDS among peacekeepers and uniformed services).
- HIV prevalence among the armed forces in the Russian Federation is 0.8%, roughly comparable to the national prevalence. Among reported cases in the military, 95% of infections are detected among recruits (UNAIDS 2005. On the front line: A review of policies and programmes to address AIDS among peacekeepers and uniformed services).
- In total, between 1986 and 2004, there were 1,012 HIV cases in the uniformed services in Peru. The highest number of infections were recorded in the police force (514), followed by the army (214), navy (208) and air force (76). (LAC COPRECOS Magazine, March 2005).

[4] Demissie K, et al. HIV-1 Infection in Relation to Educational Status, use of hypodermic injections and other risk behaviors in Ethiopian Sailors. 1996. East African Medical Journal.

[5] **Title:** HIV / AIDS in Latin America and the Caribbean.
Author: Corbin J; Ross A; Seybolt P; Mayberry L; Rudolph D; De Lay KS
Source: Washington, D.C., Bureau of the Census, International Programs Center, Health Studies Branch, 1995. v, 25, [65] p. (Research Note No. 19)

HIV prevalence among uniformed personnel, continued

Figure 8.1. HIV prevalence among Royal Thai Army conscripts, classified by their longest residency during the two years prior to recruitment



Source: UNAIDS. HIV/AIDS prevention and control: an experience of the Royal Thai Army in Thailand. July 2004.

Role of uniformed personnel in surveillance

Military recruits

Young males who are conscripted or who volunteer for military service may, in some countries, be considered relatively representative of other young males, especially if military service is mandatory. Biological and behavioural data collected from military personnel at recruitment can be used to approximate a broad cross-section of the general young male population for *surveillance* purposes.

Sero-prevalence data from military recruits can be used to gain an understanding of the epidemic in different geographic areas. When prevalence data are linked to recruits' area of residence, data may be analysed using *geographic information systems* (GIS) to gain information about trends in the epidemic in different geographic areas.

Incidence estimates

Because of their young age, the prevalence of HIV among new male recruits may serve as a proxy for HIV *incidence* among similarly aged men in the general population.

Repeated annual testing of uniformed personnel can provide information on the HIV incidence among uniformed personnel during their period of service.

Bridges with other populations

Uniformed personnel *bridge* with many other high-risk groups. They are often the clients of SWs. Furthermore, some groups of uniformed personnel may be more likely to have sexual relations with female prisoners, refugees, and other displaced persons, who themselves may be at high risk.

Additionally, many countries contribute personnel to United Nations peacekeeping operations, which often occur in areas of high HIV prevalence. Uniformed personnel infected with HIV while serving in UN peacekeeping operations in areas of high HIV prevalence may act as a bridge, bringing HIV back to their home countries.

Finally, many military personnel are married or marry shortly after their discharge from service. The wives of military and former military personnel may also be at high risk for HIV.

Conducting a Formative Assessment

The policies governing the testing of uniformed personnel vary by country. Whereas some countries have mandatory HIV testing of military recruits, others do not.

The first step in planning HIV surveillance in uniformed personnel is to identify the various points of access, locations of uniformed personnel, barracks and health clinics used by military and police and other places where surveillance can be conducted.

Listed in Table 8.1 below are recommendations for proposed surveillance methods for military, police, and law enforcement personnel:

Table 8.1: Recommendations for proposed surveillance methods, uniformed personnel

- Form a collaborative group with the command structure of the organisation which you are targeting. Build key *alliances* with command structure for uniformed personnel, including command staff and medical officers at clinics caring for these persons.
- Conduct a situation analysis.
- Conduct *formative assessment* to identify the groups of members of uniformed services at highest risk of HIV infection.
- Understand the definition of uniformed personnel and what groups might be included in your country.
- Assess the infrastructure of military and law enforcement authorities for surveillance purposes.
- Gain collaboration of existing personnel delivering public health interventions, if applicable.
- Design surveillance approach.
- Collect HIV sero-prevalence data, behavioural data, and STI data.
- With the collaboration of the uniformed service analyse and disseminate data.

Formative assessment

Conducting formative assessment will help you identify key *indicators* to measure the diversity of the sub-populations of uniformed personnel and the infrastructure available for surveillance purposes.

A formative assessment will help answer the following questions:

- What are the different types of uniformed personnel in your country (for example, military personnel and police officers)?
- Are there HIV/AIDS policies in place for the uniformed service(s)?
- What are your country's policies for recruiting uniformed personnel?
- Is military service mandatory or voluntary?
- Are uniformed personnel routinely screened for HIV at recruitment or at any other time during their service?
- Are surveys of uniformed personnel feasible and ethical?
- Are surveys of uniformed personnel at time of discharge feasible?

Forming alliances

Access to uniformed personnel is usually restricted. Senior commanders and medical officers are important *gatekeepers* who can provide access to uniformed personnel. Prior to beginning surveillance activities, the surveillance team will need to form alliances at the highest levels, with the Ministry of Health and the Ministry of Defence for armed services, or with the Ministries of Interior or Justice for police. It will also be helpful to enlist the support of those operating the current medical care and public health intervention programmes that exist for these populations. This will be helpful in setting up the infrastructure for the surveillance system.

Selecting a Sampling Method

Many countries have routine physical examinations for uniformed personnel. As part of these examinations, HIV testing may be required. This is the ideal situation and allows for non-biased estimates of HIV prevalence.

In situations where no routine testing exists, however, surveys can be done as *repeated cross-sectional studies* in a random sample of personnel. Another option, although a less desirable one, is to conduct surveys of persons seeking treatment for STIs at military clinics.

When routine testing is not used, prevalence surveys can be combined with behavioural survey methods to produce a more complete understanding of HIV, STIs, and *risk behaviours* in these populations. Sampling is desirable because is may be logistically difficult for HIV surveillance programmes to reach all uniformed personnel.

Selecting a Sampling Method, continued

Uniformed personnel may or may not be tested for HIV on a regular basis. The following table summarises what you should do in each case:

Table 8.2. Recommended type of sampling, depending on whether uniformed personnel are routinely tested for HIV.

Routine testing?	Sampling options	More information
Yes	▪ Use all the data available ▪ Choose a survey period of a few months	▪ The advantage of choosing a shorter survey period is that you may be able to ask additional behavioural questions
No	▪ Conduct a survey of a random sample ▪ Try to access persons through medical clinics	▪ Because lists of personnel likely exist, random sampling methods can be quite straightforward: ▪ ask individual service members to participate (with their commanders' permission) ▪ surveys can include biological and behavioural variables ▪ if repeated regularly, surveys can provide good monitoring systems for HIV, STI and behavioural risks ▪ An alternative is clinic-based surveys: ▪ survey all individuals seeking care, or just a sub-set (for example, those who have STI symptoms) ▪ people who are sick are more likely to seek care, so this will likely lead to overestimation of the true prevalence

Selecting a Sampling Method, continued

When uniformed personnel are not routinely tested for HIV, the following random sampling methods may be appropriate:

Systematic sampling - Every *n*th person is sampled from a sampling frame after a random start. Systematic sampling often is used instead of simple random sampling when the sampling list is long or the desired sample size is large, or when access is at a clinic. Random sampling may be difficult due to a lack of computerised personnel lists and due to security concerns.

Cluster sampling - When it is difficult or impossible to make a list or sampling frame of each individual in the target population, you can develop a sampling frame of some larger unit. These are called *clusters* or *primary sampling units*. A cluster is any aggregate of the population of interest (for example, people in recruitment centres, military units, or military bases or camps). Cluster sampling is the most common method of sampling in surveys. Once the clusters are selected, you need only list the people in the selected clusters. All members of the target population still have a chance of being sampled (a non-zero probability) as long as all the clusters containing the target population are included in the list of clusters.

Stratified sampling - Stratification is the classification of a survey population into sub-groups or strata on the basis of selected characteristics (such as members of the army, navy, police force, or air force). Stratified sampling is the selection of separate (that is, independent) samples from each stratum.

Measures and Indicators

Both behavioural and biologic information on HIV, STIs, and risk behaviours can be collected in a variety of ways, with a focus on sexual transmission and risk. It is important to note, however, that there may not be enough time, ability, or organisational interest to conduct behavioural surveillance in these settings. Ideally, surveillance among uniformed personnel should be conducted on a regular basis, every year.

Biological measures

Measuring HIV sero-prevalence among uniformed personnel is an integral component of surveillance. The high sexual risk among uniformed personnel also makes STI testing a useful and feasible indicator for surveillance (see Appendix E: Laboratory Tests Available for Measuring Biological Outcomes among High-Risk Groups for a description of the available STI tests)..

Possible biological measures to include in addition to HIV testing when conducting surveillance among prisoners are presented in Table 8.3.

Table 8.3. Possible biological measures to include in prisoner surveillance

Biological Measure	Notes
Syphilis	Often is the most efficient biological indicator because the standard tests can be done with the same serological specimen as used in HIV testing. The test is relatively inexpensive and widely available
Gonorrhoea	Accurate tests are expensive and require a urine specimen
Chlamydia	Accurate tests are expensive and require a urine specimen
Herpes simplex virus type 2 (HSV-2)	A marker for lifetime sexual risk but less available. To be an indicator for sexual risk, the test must distinguish HSV-2 from *HSV-1*

Behavioural measures

Measuring changes in sexual behaviour among uniformed personnel helps explain trends in HIV and STI prevalence data. Among uniformed personnel, new behavioural trends may emerge rapidly, particularly when programmes and resources are targeted toward promoting safe behaviour in this group.

Several international organisations have sought to standardise a set of "core" or basic indicators of HIV risk among uniformed personnel. These include:

- percentage of respondents who received HIV testing in the last 12 months and who know the results (*United Nations General Assembly Special Session on HIV/AIDS* [UNGASS])
- percentage of respondents who both correctly identify ways of preventing the sexual transmission of HIV and reject major misconceptions about HIV (UNGASS)
- percentage of respondents who have had sex with a non-marital, non-cohabiting partner in the last 12 months (MEASURE)
  - number of respondents who report using a condom the last time they had sex with a non-marital, non-cohabiting partner
- percentage of respondents reporting they had sex with an SW in the last 12 months (MEASURE)
  - number of male respondents reporting condom use the last time they had sex with an SW
- percentage of respondents who have had anal sex with more than one male partner in the last 12 months (MEASURE)
  - percentage of men or their partners who used a condom at last anal sex with a male partner
- percentage of respondents with a self-reported STI (urethral discharge).

These basic indicators may be supplemented with local measures of particular importance in your area, as determined by your formative research phase. These additional indicators may include:

- perceptions of self and/or partner risk
- type of partner(s)(including SWs)
- alcohol and drug use
- migration, mobility
- STI treatment-seeking
- marital status
- history of deployment to conflict or refugee areas.

Reference to indicators

Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found in Unit 1.

Indicators recommended by international bodies will not necessarily capture all behaviours relevant to your area. Some questions will be for local use only (for example, exposure to specific prevention programmes or assessing particular risky practises or situations). The formative assessment phase should be used to determine the local questions of greatest relevance to the epidemic in your area. In addition, the wording of the indicators will have to be translated and field-tested in your local languages.

Special Ethical Considerations

Counselling and testing

Providing HIV counselling and testing, and referrals to care and treatment for HIV-infected people should be considered where feasible; it provides many benefits over surveillance alone. Uniformed personnel can be trained to provide counselling and testing—skills which can be integrated into regular service provision once the survey is over. Individuals can be offered their HIV test results, giving them the opportunity to present for care. Choice and confidentiality are of the utmost importance. Survey participants always should be allowed to decline any or all participation in the survey or in knowing their HIV test results.

Obtaining informed consent

When conducting HIV testing among uniformed personnel, you must determine whether the testing is being done for clinical reasons or for surveillance reasons. Mandatory testing of all new recruits is performed for clinical reasons. Local laws and regulations cover how this type of testing is to be done, but there is no reason to ignore data obtained from mandatory screening for estimating the prevalence of HIV among new recruits. *Informed consent* is required when conducting prevalence studies and other activities involving the non-routine collection of data. All data-collection activities other than mandatory or clinical testing usually require informed consent.

Uniformed personnel are under unique constraints because of the hierarchical structure of uniformed services. The subordinate position of some uniformed personnel may affect their ability to make a truly voluntary and un-coerced decision whether or not to participate as research subjects. It is important to take special precautions when obtaining informed consent from uniformed personnel.

Assuring confidentiality

Confidentiality protects subjects from the negative consequences that may arise from participating in a study or survey. The confidentiality of medical information of uniformed personnel may be difficult to maintain.

People asked to participate in a survey or study should understand potential threats to their confidentiality. They should also understand the steps that the investigators will take to minimise them. Explaining these issues to potential participants is part of the informed consent process.

Assuring confidentiality, continued

Steps you can take to minimise threats to confidentiality may include:

- conducting interviews with uniformed personnel in private settings
- keeping names of individuals separate from the data collected about them
- limiting access to any identifying information to authorised study personnel only
- keeping study documents in a locked, limited-access room
- having all staff sign confidentiality forms and undergo training in research ethics.

Some countries exclude HIV-infected persons from serving in the military or police force; in these settings, ensuring confidentiality may not possible.

When confidentiality cannot be guaranteed, the potential harm of being identified as HIV-infected is severe, and blood specimens are routinely collected for other purposes, such as syphilis screening, *unlinked anonymous testing* (UAT) may be desired. By design, UAT precludes the disclosure of participants' names or other identifying information. Module 3: HIV Surveillance covers the methods of UAT in detail.

Summary

Throughout the world, uniformed personnel are among the populations most susceptible to HIV. They are at high risk of infection because they are often away from home and surrounded by opportunities for casual sex, often with female SWs. Where military service is mandatory, young male recruits may be considered relatively representative of other young males. Many countries have routine physical examinations for uniformed personnel, including routine HIV testing. Although this information is collected for clinical purposes, collecting it for surveillance purposes allows for a non-biased estimate of HIV prevalence. It should be noted that uniformed personnel are under unique constraints because of the hierarchical structure of uniformed services. It is important to take special precautions when obtaining informed consent from uniformed personnel.

NOTES

Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of this unit. Make any changes you want to make. We will discuss the questions and answers in a few minutes.

Small group discussion

Get into small groups to discuss these questions.

1. Does your country conduct behavioural and/or sero-surveillance of uniformed personnel?

2. In your country, who are the gatekeepers of this population?

3. In your country, what methods have been used to sample uniformed personnel?

4. In your country, what behavioural and biological measures have been used when conducting surveillance of uniformed personnel?

5. In the past five years, has the prevalence of HIV among uniformed personnel increased, decreased, or remained about the same?

Apply what you have learned/ case study

HIV Surveillance in Globa's Armed Forces

Part 1: Collecting information to plan surveillance activities

The current HIV prevalence in the general population of Globa is 0.5%. Globa does not currently test military recruits for HIV, nor does it periodically test servicemen. As a pilot initiative, an army base in the port city of Sadcity performed UAT on leftover sero-specimens collected between May and December of last year. Results showed an HIV prevalence of 5.5% among the 214 military personnel included in the sample.

The Defence Minister considers that the containment of HIV/AIDS is a top priority in combat preparation and is alarmed at the high rates of HIV found in last year's survey of military personnel.

The Minister believes that it is crucial to have knowledge about the health status of military personnel. This information will help avoid a sudden incapacity in military readiness due to AIDS. It also will allow evaluation of whether there are sufficient HIV-negative troops to provide the blood transfusions necessary for combat surgery and other catastrophes. The Minister calls on the Director of Epidemiology and Surveillance for the Ministry of National Defence to design a sero-behavioural survey to reveal the prevalence and epidemiology of HIV in the military. It is the Minister's hope that the results from this survey will assist in policy making, creating entry criteria for recruits, planning medical services, and designing training activities for HIV prevention.

1. What information is required for planning the survey?

2. How will the epidemiology and surveillance team obtain this information?

Part 2: Choosing a sampling approach

Before conducting the surveillance, the surveillance team must carry out formative research to catalogue the various points of access, locations of uniformed personnel, and health facilities used by military personnel. The surveillance team conduct a pre-surveillance assessment to assess the infrastructure available for surveillance and to determine if military personnel are routinely tested for HIV.

Because the surveillance team is conducting this surveillance activity on behalf of the Ministry of National Defence, they can reach this usually restricted-access population. Before beginning surveillance activities, the surveillance team enlist the support of the directors of the various military medical centres.

The surveillance team decide to include 600 male military personnel aged 18 years and older. There are over 50 military installations in Globa. The country is divided into three military regions:

- Northern Region: 10 bases
- Central Region: 25 bases
- Southern Region: 15 bases
- Each military base houses one division of 5,000 men.

The team decide that it is not necessary to include personnel from all installations, only to have the sample reflect the relative military strength of each region.

1. What sampling approaches are appropriate for obtaining a representative sample of military personnel?

Part 3: Collecting biological and behavioural data

A variety of sampling approaches are appropriate for sampling military personnel in Globa. As military personnel are not routinely tested for HIV, universal testing using UAT is not possible. A cross-sectional survey, however, can be conducted in a random sample of personnel.

The surveillance team opt for a two-stage cluster sampling design. They stratify the bases by region and select every fifth base. Because lists of the military personnel associated with each base are available, the team then randomly select 60 respondents from each of the 10 selected military bases.

Northern District – 120 participants
Great Gorge – Air Base.....(60)
Port Marina – Army Base .....(60)

Central District – 300 participants
Hidden City – National Army Training Centre .....(60)
Hidden City – National Air Force Training Centre .....(60)
Hidden City – National Special Forces Training Centre .....(60)
Sabina – Air Base for the Central District .....(60)
Sabina – Army Base for the Central District .....(60)

Southern District – 180 participants
Sadcity – Sadcity Naval Centre .....(60)
Sadcity – Army Base .....(60)
Sadcity – Air Base ..... (60)

1. What biological and behavioural information should the epidemiology and surveillance team collect?

2. What are some of the ethical considerations for this surveillance activity?

Part 4: Analysing and disseminating data

The surveillance team decide to collect information on the social and demographic characteristics of the study population and to assess the sample's HIV-related risk behaviour and knowledge, attitudes, and practises regarding HIV/AIDS. To determine the prevalence of HIV and syphilis in the military population, the surveillance team decide to collect blood samples and provide confidential syphilis testing, HIV rapid testing, and referrals to treatment for men who are found to be infected.

With input from behavioural scientists, statisticians, and epidemiologists, the surveillance team develop a questionnaire based on Globa's Demographic Health Survey (DHS). The final version of the questionnaire was pre-tested. Feedback and comments also were obtained from counsellors conducting the survey.

The surveillance team discuss the many ethical issues related to conducting research among military personnel. Because this surveillance activity involves the non-routine collection of data, informed consent must be obtained from all participants. Recognising that military personnel may be under unique constraints because of the hierarchical structure of uniformed services, the HIV surveillance team take special precautions when obtaining informed consent from these people. Counsellors from the surveillance team explain the purpose and procedures of the survey, as well as the HIV testing procedures, to the potential participants in group settings. All participants are told that they can choose to participate or not, without negative consequences. After the group presentation, each potential participant is briefed again in private and his questions are answered by the counsellor. At this time, the volunteer is given a written copy of the consent form to review, fill out, and sign. All participants are given a written copy of the consent form to keep for future reference.

Counsellors administer the face-to-face interviews in private, using a standard, structured questionnaire. Blood samples are taken from finger-prick for linked, confidential, HIV rapid testing, and from dry blood spots. Results are given to those who choose to receive them and referrals to care are made where indicated.

Part 4: Analysing and disseminating data, continued

This surveillance activity produced the following results:

Social and demographic information:

- A total of 600 male military personnel from 10 military installations were included in this survey
- Median age of respondents was 22 years
- The majority of respondents were unmarried (56%, 336/600).

HIV prevalence:

- Of the 600 samples tested, 18 (3%) appeared positive for HIV-1 antibodies
- The prevalence of HIV was significantly higher among personnel from the three military installations in the port city of Sadcity in the Southern Province (12/180, 6.7%) compared to personnel from the Northern and Central Provinces (1.4%)
- Prevalence of syphilis antibodies was 7% (42/600), increasing by age and correlated to HIV-1 positive serology (p=0.001) and with 24% (10/42) active cases

HIV-related risk behaviour:

- 42% (252/600) of respondents reported that they had sex with an SW in the last 12 months
- Nearly all interactions with SWs occurred at brothels located near the military bases
- 62% (156/252) of the respondents who reported having sex with an SW reported using a condom the last time
- No injection drug use was reported.

HIV-related knowledge and attitudes:

- 32% (192/600) of respondents reported having been previously tested for HIV testing, although only 60% (115/192) of those previously tested reported knowing the test result
- Nearly all (88%, 528/600) respondents correctly identified consistent condom use as a way of preventing the sexual transmission of HIV.

- What interventions/programmes should be developed based on these results?

Part 5: Epilogue

The results of this surveillance activity confirm the results of last year's study which found HIV prevalence among military personnel to be significantly higher than that of the general population. The majority of the military personnel included in the survey were unmarried, and many reported having sex with an SW within the previous 12 months. Although most respondents were correctly able to identify condom use as a method of preventing the transmission of HIV, many respondents did not use a condom the last time they had sex with an SW.

The surveillance team present the following recommendations to the Defence Minister:

- provide more confidential voluntary counselling and testing (VCT) at military health centres
- provide treatment and care for personnel found to be HIV-infected
- work with brothels near military bases to establish 100% condom-use programmes.

NOTES

Unit 9

Out-of-School Youth

Overview

What this unit is about

This unit describes the background and special considerations for conducting behavioural and biological HIV surveillance among out-of-school youth.

Warm-up questions

1. Out-of-school youth may include which sub-populations?

   a. street children
   b. child labourers
   c. adolescent sex workers
   d. married adolescents
   e. all of the above

2. True or false? By targeting youth through behaviour-change campaigns, several countries have successfully decreased national HIV prevalence levels.

   True False

3. List three possible places where you would expect to find large numbers of out-of-school youth.
   a.

   b.

   c.

4. What are two reasons why out-of-school youth may be considered a vulnerable population?

   a.

   b.

Introduction

What you will learn

By the end of this unit, you should be able to:

- understand the diversity of out-of-school youth
- understand the role of out-of-school youth in the HIV epidemic
- describe options for sampling out-of-school youth for surveillance
- describe the special ethical considerations associated with conducting HIV surveillance activities among out-of-school youth.

Background

Barriers to education

In some of the countries most affected by HIV/AIDS, many children and adolescents are not in school. Factors that can contribute to children not attending school include:

- Economic hardship—due to school fees, such as tuition, books, uniforms, some families are not able to afford sending their children to school.
- Household obligations—some families rely on older children to do housework, childcare, or work outside the home to supplement family income.
- Gender discrimination—families may not believe that educating girls is important.
- Insufficient or inappropriate education—lack of schools or shortage of trained teachers may narrow educational opportunities.
- Poor infrastructure—poor roads or transportation systems may prevent youth from getting to school.
- National policies may prevent some persons from attending school; for example, policies may prohibit pregnant girls or persons without birth certificates from attending school.
- The lure of cities—youth may run away from families in rural areas.
- Social conflict and emergencies—natural disasters and political conflicts may disrupt school schedules.
- Orphan status—parents may have died from AIDS.

Barriers to education, continued

In many countries, females are less likely to attend school than males.

- Girls are more likely than boys to be kept at home when there is a need for household help, particularly when there are sick family members or younger siblings who need care.
- Because of economic or cultural beliefs, families may choose to send only their male children to school.
- Girls marry at a young age, which in most cases permanently disrupts their education.

Definitions

O*ut-of-school youth* (OSY) include diverse sub-populations. For the purpose of this unit, we consider OSY to include children and adolescents from the ages of 15 to 24 years who are not currently enrolled in formal education. They may have completed school, may have dropped out of school, or may never have started school. The experiences of OSY vary greatly—they may work in factories, sell goods in markets, work on farms, stay at home to do housework or child-rearing, engage in sex work, live and work on the streets, or be unemployed.

Sub-populations of out-of-school youth

OSY often live under challenging conditions and are marginalised from mainstream services and society. OSY at risk of HIV infection can be grouped into one or more of the sub-populations discussed in the table below.

Table 9.1. Sub-populations of out-of-school youth

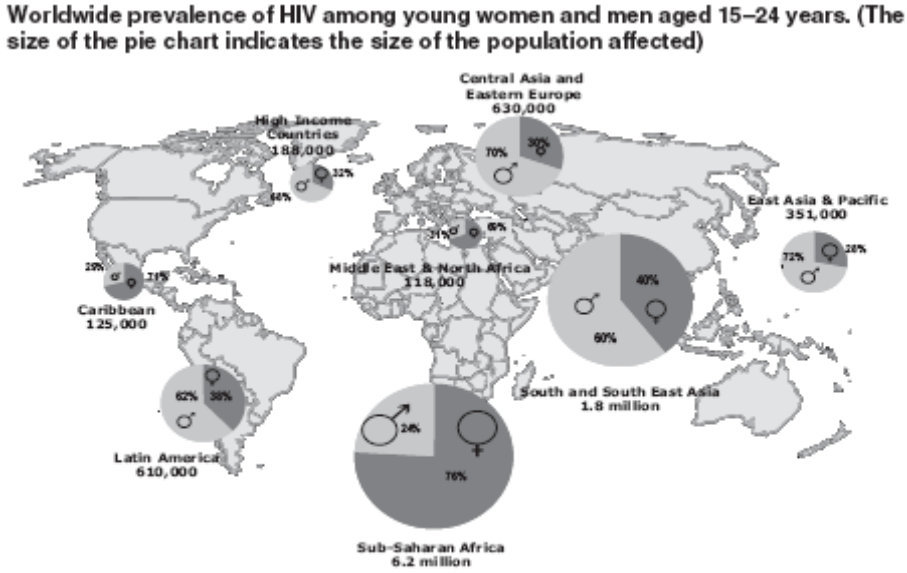
Group	Definition
Street children	Includes orphaned, homeless, runaway or neglected children who live chiefly in the streets without adequate protection, supervision, or direction from responsible adults.
Child labourers	Includes children who are paid to do work that is physically, mentally, or morally exploitive and harmful in its own right, or because it blocks their access to education. These children often migrate from rural areas to cities to work.
Adolescent sex workers	Includes any person under the age of 18 years who is involved in the sex industry. Adolescent *sex workers* (SWs) often do not have the ability to resist sexual aggression or make demands that their clients use condoms.
Married adolescents	Includes girls who are married before the age of 18 years due to family traditions. Due to household responsibilities, married adolescents generally do not attend school.

Role of OSY in the HIV epidemic

Youth who do not attend school have a higher risk of acquiring HIV, as they:

- do not receive reproductive health education and other school-based services
- may have low self-esteem
- are not exposed to the structure that the school environment would otherwise provide
- face *stigma* and discrimination, which prevent them from adopting risk-reduction behaviours
- are more likely to experiment with drugs and alcohol
- may be sexually exploited, trafficked, or involved in the sex industry.

Figure 9.1. Worldwide prevalence of HIV among young women and men aged 14-24 years.



Source: UNAIDS, UNICEF 2004 (Updated from reference (*70*))

Source: Preventing HIV in Young People: A systematic review of the evidence from developing countries: UNAIDS interagency task team on HIV and young people. Ross, Dick and Ferguson. WHO 2006

Figure 9.1 refers to the worldwide prevalence of HIV among youth aged 15-24 years. In the Asia and Pacific region, it is estimated that over 2 million young people aged 15-24 years are living with HIV, with widening epidemics in many countries in the region.[i] In sub-Saharan Africa, it is estimated that 6.2 million young people aged 15-24 years are living with HIV. This is nearly two thirds of all young people living with HIV or AIDS worldwide.[ii]

Role of OSY in the HIV epidemic, continued

Young people account for the most infections in eastern Europe and Central Asia, where nearly half of adults living with HIV or AIDS (600 000/1.3 million) are younger than 25 years; most of them are male.[iii] Young people often are more likely to engage in *high-risk behaviour*, making them more susceptible to the risk of infection. Reasons for increased risk-taking among youth are:

- lack of information
- peer pressure
- inability to calculate risk
- low perception of risk
- economic pressures
- inability to refuse unprotected sex
- limited availability of or access to condoms
- lack of youth-friendly services.

The types of risks and social factors underlying HIV infection among OSY categories differ, as outlined in Table 9.2, below.

Table 9.2. The vulnerability of OSY to HIV

Group	Risk and social factors
Street children	▪ are often sexually active ▪ may have multiple sex partners; eg, female SWs ▪ may provide sex in exchange for money ▪ may be sexually abused ▪ may inject drugs ▪ have less prevention information through schools ▪ may be involved in gangs and/or drug trafficking ▪ generally do not receive appropriate medical care
Child labourers	▪ have less prevention information through schools ▪ may be sexually abused in the workplace ▪ may be involved in sex work
Adolescent sex workers	▪ may not have the ability to resist sexual assault ▪ are often obliged to take multiple clients each day ▪ are young and physically immature, which, combined with the physical trauma of aggressive or repeated intercourse, makes them especially susceptible to contracting and spreading HIV
Married adolescent women	▪ may not be able to control a husband's infidelity or resist sexual abuse ▪ are more prone to STIs due to immature genital tracts ▪ have less prevention information through schools

Role of OSY in the HIV epidemic, continued

By targeting youth through behaviour-change interventions, several countries have successfully decreased national HIV *prevalence* levels. To create appropriate interventions, HIV *surveillance* of high-risk youth is crucial.

Prevalence of HIV among OSY

Overall, the prevalence of HIV among OSY varies by country and region, as illustrated by the following data from Asia:

- In Nepal, 11% of the reported HIV cases are among youth younger than 19 years of age.[iv] (ASIA)
- In Bangkok, Thailand, the prevalence of HIV among *men who have sex with men* (MSM) aged 22 years or younger has risen from 13% in 2003 to 22% in 2005.[v] (ASIA)
- In Myanmar, the prevalence of HIV among young people aged 15-24 years was found to be 2.2% in 2005, compared to a national adult HIV prevalence of 1.3%.[vi] (ASIA).

The prevalence of HIV among OSY is relatively unknown in most of the world; however, there have been a few knowledge and behaviour surveys, as illustrated by the following data from Africa:

- In Addis Ababa, Ethiopia, being out-of-school, male, aged 20-24 years, and consuming alcohol and khat (an amphetamine-like substance) predicted the likelihood of engagement in sexual activity. Compared with in-school youth in the same study, higher proportions of OSY were involved in sexual activity (46.3% vs. 18.1% respectively) and only half reported condom use at last sex.[6]
- A sample of 60 of female OSY in Lusaka, Zambia, found that a number of them were engaged in high-risk sexual behaviour, including unprotected anal intercourse, the majority having sex primarily with middle-aged men.[7]
- In a behavioural surveillance survey among OSY in Guyana it was found that 34% had more than one regular partner in the past 12 months, 2% had been tested for HIV, and over half reported knowing someone who was HIV-positive (Guyana BSS 2003/2004, MOH).

[6] Taffa N et al. Psychosocial determinants of sexual activity and condom use intention among youth in Addis Ababa, Ethiopia. International Journal of STD & AIDS. 2002.
[7] Feldman, D.A. High-risk sexual behavior among some female Zambian out-of-school adolescents: A possible future application of the value utilization/norm change model. Paper presented the Society for Applied Anthropology Meeting, Albuquerque, USA.

Role of OSY in surveillance

The HIV epidemic varies greatly in different regions of the world, but in each of these epidemics young people are at the centre. It is crucial to identify and track high-risk groups within this population. Because of the high-risk behaviour and ability to make long-lasting behavioural changes, many special programmes and interventions target OSY, including:

- mass media campaigns
- promotion of youth-friendly health services
- promotion of condom use and life skills
- *voluntary counselling and testing* (VCT) and *sexually transmitted infection* (STI) treatment.

Because young people are often powerful agents for change when given the appropriate tools and support, it is crucial to have surveillance in place to monitor specific behaviour changes in these groups.

Overlap with other populations

In many areas, young people constitute a significant percentage of female SWs, *injection drug users* (IDUs), and MSM. As an example:

- In Cambodia, Laos, Myanmar, and Viet Nam, between 60% and 70% of SWs are younger than 25 years of age.[vii]
- A study among female SWs in India indicated that the highest HIV *sero-prevalence* was among the younger SWs (≤20 years of age), with 12% testing HIV positive.[viii]
- In Eastern Europe, 40% of newly diagnosed HIV infections among IDUs were estimated to occur among those aged 15-24 years.[ix]
- In Jamaica, 50% of female SWs reported that they had begun sex work by their 18th birthday.[x]
- In Eritrea, a survey found that 12% of female SWs aged 15-19 years and 24% of those aged 20-24 years were HIV positive.[xi]
- In a study in Lima, Peru, conducted among MSM, 50% were younger than 25 years, and 18% of the men (of all ages) were HIV positive.[xii]
- In a study in Moscow, 40% of male SWs were aged 19 years or younger, with another 45% being between the ages of 20 and 24.[xiii]
- In Central Asia and Eastern Europe, 14% to 20% of new diagnoses attributed to transmission by MSM have been reported to occur among young people aged 15-24 years.[xiv]

Conducting a Formative Assessment

The first step in planning HIV surveillance in OSY is to gain a better understanding of the sub-populations of OSY in your area.

Formative assessment

Formative assessment activities are conducted to identify key *indicators* to measure the diversity of the sub-groups of OSY and the geographic areas and venues where OSY may be found in large numbers. The aims of the formative process include:

- exploring the diversity and types of OSY
- agreeing on the purpose and uses of surveillance data for OSY programmes
- identifying a co-ordinating or decision-making body
- selecting which specific OSY sub-groups to include
- delineating the geographic coverage areas
- selecting which indicator variables to collect (behavioural and biological).

Because OSY are composed of a number of different sub-groups, HIV prevalence may differ considerably among different groups existing relatively close together within a given country, or even within a given city. Identifying points of access and forming *alliances* with organisations and persons trusted by the different OSY sub-groups will help you more fully understand the culture and diversity of OSY in your area.

Consider where to find OSY

Surveillance requires gaining access to a full range of OSY and areas where OSY can be found. Access may be difficult when considering each sub-group's different characteristics. Findings from the formative assessment should prove helpful in focusing the search. To facilitate locating and accessing OSY, consider:

- identifying and interviewing those who have contact with OSY
- visiting areas where they are known to congregate
- collaborating with organisations that provide education, food, and shelter to OSY, such as religious organisations and civil society organisations.

Possible organisations that can help you locate and access OSY include:

- the United Nations Children's Fund (UNICEF)
- the United Nations Populations Fund (UNFPA)
- the Red Cross and Red Crescent societies
- Save the Children
- the World Association of Girl Guides and Girl Scouts
- the Boy Scouts
- OXFAM International
- local sports clubs.

Other OSY sub-groups, such as child SWs, factory workers, and soldiers, may require more extensive formative assessment before they are located. These sub-groups may be more easily accessed by forming key alliances with adults or older youth who are in charge. Some examples include:

- influential current and former SWs
- factory workers
- police
- leaders of youth gangs
- handlers or other *gatekeepers,* such as pimps, madams, brothel managers and owners, and factory supervisors
- governmental and *non-governmental organisations* (NGOs) conducting youth-targeted HIV prevention and care programmes
- national and international advocacy groups dealing with OSY issues.

These people and organisations also can assist later in implementing surveillance activities. Former adolescent SWs, for example, can be hired and trained as recruiters or to conduct interviews in difficult-to-access areas.

Conduct ethnographic mapping

Ethnographic mapping entails the creation of a comprehensive description of the population with respect to:

- the places OSY can be found
- time periods of high and low volume of OSY
- types of OSY sub-groups found in a particular area.

This comprehensive description is used to broadly guide where and when OSY can be found and recruited for surveillance activities and what sub-groups can be found in different areas. More specifically, detailed ethnographic mapping can be used to produce a *sampling frame* or comprehensive roster of OSY or a particular sub-group in your area. This sampling frame is the basis for some *probability-based sampling* methods.

Conduct ethnographic mapping, continued

The locations where OSY spend most of their time will differ by sub-group. To locate OSY, identify areas where young people tend to congregate. These include:

- parks
- markets
- beaches
- train and bus stations
- street corners
- movie theatres
- sports fields
- shelters.

Depending on the focus of the surveillance, other sub-groups, such as OSY sex workers, intravenous drug users or factory workers may be included. In these cases, consider:

- brothels
- sex trade areas
- bars and discos
- massage parlours
- areas where people gather to use, sell, or buy drugs
- truck stops
- factories employing youth workers
- households.

Due to various legal issues surrounding many of the sub-groups, it is unlikely that there is any formal registration system for OSY. Depending on each country or region, however, OSY may be registered as SWs or labourers. Rosters of OSY may also be available from NGOs, religious organisations, and other agencies that provide services to OSY. It is important to note that these lists are rarely separated into adult and youth categories, making it difficult to obtain a representative sample.

Selecting a Sampling Method

Hard-to-reach populations, such as OSY, may be sampled using either probability sampling or *non-probability sampling* (also referred to as *convenience sampling*). Depending on the organisation, accessibility, and the extent that OSY are networked, different sampling methods may be more or less feasible. Although non-probability sampling, such as *snowball sampling*, is easier to conduct than probability sampling, as a sampling frame is not needed, data collected through non-probability methods can introduce *bias* into the data. This can occur due to a number of reasons, such as differences in HIV prevalence or risk behaviours between different sub-populations within a group or between the sub-groups themselves. Probability and quasi-probability sampling methods can be used to obtain more representative samples of OSY.

Not all OSY are difficult to access. Many OSY are married or live with relatives. These youth can be sampled using conventional sampling techniques. To obtain an accurate list of OSY, review recent survey results from Demographic Health Surveys (DHS), or behavioural *surveillance surveys* (BSS). These surveys often contain a comprehensive listing of household members and can be used to help create a sampling frame.

Probability sampling techniques, such as *time-location sampling* (TLS) and *respondent-driven sampling* (RDS) may be used to sample hard-to-reach OSY like street children.

Time-location sampling

Time-locations sampling (TLS) may be used to sample OSY when OSY tend to gather or congregate in identifiable and accessible locations, such as certain street corners, markets, and transportation centres. In TLS, the sites known to be frequented by OSY (found through ethnographic mapping or formative activities) are used to develop a sampling frame from which a probability sample of sites and time periods are chosen. Because the locations where OSY congregate may change over time, you should develop a new sampling frame for each round of surveillance.

Respondent-driven sampling

Certain OSY sub-populations do not congregate in identifiable and accessible locations, and are not adequately represented by TLS. Respondent-driven sampling, an adaptation of chain-referral sampling, is based on a dual incentive structure in which participants are rewarded for being interviewed and for recruiting their peers. When using RDS to sample hard-to-reach or mobile OSY, *incentives* should not be too weak or too strong.

- If incentives are too weak, participants may feel the compensation is not worth the time it would take to recruit their peers.
- If incentives are too strong, bias can be introduced, as the participants may try to keep the incentives distributed solely with in their own peer group.

Food items are often used as incentives when conducting RDS among children and adolescents. Organisations working with street children can help you determine appropriate incentives.

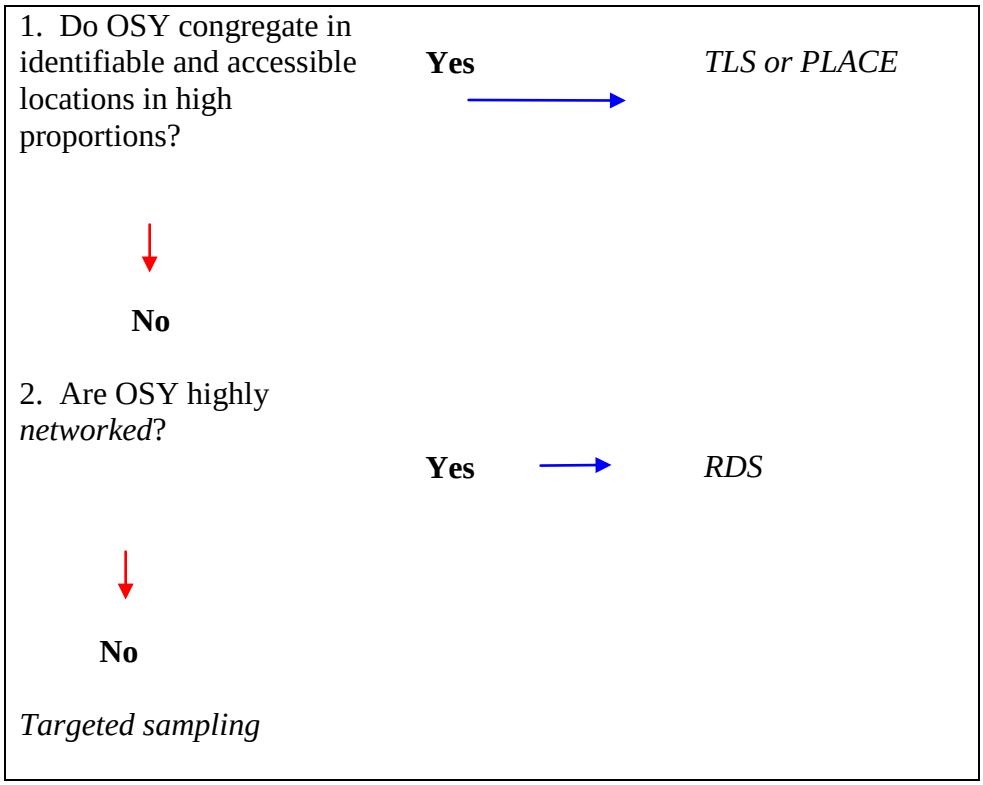
As the definition of OSY may vary, your inclusion and exclusion criteria should be very clear in the first wave of recruitment so that youth understand which other youth to recruit.

Priorities for Local AIDS Control Efforts

The *Priorities for Local AIDS Control Efforts* (PLACE) protocol is a new rapid assessment tool used to identify areas of high transmission that formalises the collection of information. PLACE uses *key informants* to identify locations where people meet new sex partners, then interviews people there to characterise the site in each area and to map sites. PLACE also interviews individuals socialising at the site to describe the characteristics of the people that gather there.

Figure 9.2 will help you select an appropriate method for sampling OSY in your area.

Figure 9.2. Selecting sampling methods for OSY



Additional information on the sampling methods that may be used to sample out-of-school youth are discussed in Module 5: Surveillance of HIV Risk Behaviours.

Measures and Indicators

Biological measures

Measuring HIV prevalence among OSY is an integral component of surveillance. The high sexual risk among many of the sub-groups makes STI testing a useful and feasible indicator for surveillance (see Appendix E: Laboratory Tests Available for Measuring Biological Outcomes among High-Risk Groups for a description of the available STI tests).

- *Syphilis* testing is often the most efficient biological indicator of unprotected intercourse because the standard tests can be done with the same serological specimen as is used in HIV testing. The test is relatively inexpensive and widely available.
- Accurate tests for *gonorrhoea* and *Chlamydia* are expensive and usually require a urine, rectal, or pharyngeal specimen.

In areas where there is suspected overlap between OSY and IDUs, biological markers may include *hepatitis C virus* (HCV).

Behavioural measures

Measuring changes in sexual behaviour among OSY helps explain trends in HIV and STI prevalence data. Among OSY, new behavioural trends may emerge rapidly, particularly when programmes and resources are targeted to promote safe behaviour in this group.

Indicators that assess sexual risk include:

- correct identification of ways of preventing the sexual transmission of HIV and rejection of major misconceptions about HIV transmission
- age of sexual debut
- condom use during last sex with a non-regular sex partner
- the use of transactional sex.

In areas where there is suspected overlap between OSY and other high-risk groups (for example, female SWs, MSM, or IDU), consider using indicators that assess high-risk behaviours in these groups.

The indicators that may be appropriate in situations where there is suspected overlap between OSY and other high-risk groups are presented in Table 9.3, on the next page.

Behavioural measures, continued

Table 9.3. Additional indicators to include when there is suspected overlap between OSY and other high-risk groups.

Group	Indicators
Female sex workers (SWs)	▪ venue of sex work ▪ number of paying customers ▪ condom use with paying customers
Injection drug users (IDUs)	▪ frequency of injection drug use ▪ sharing of needles, syringes or other injecting equipment ▪ types of drugs injected ▪ history of imprisonment
Men who have sex with men (MSM)	▪ number of male sex partners ▪ frequency of *unprotected anal intercourse (UAI)* ▪ frequency of *unprotected receptive anal intercourse (URAI*)

Reference to indicators

Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found at the websites listed in Unit 1 of this module.

Special Ethical Considerations

Because OSY are young and often involved in activities such as prostitution or child labour, they are often stigmatised and considered a *vulnerable population*. Their participation in surveillance activities may place them at risk for harm and discrimination. These risks include:

- loss of anonymity (such as inadvertent identification as a drug user, SW, or undocumented labourer)
- inadvertent disclosure of HIV status
- negative reaction and backlash in response to publicised results.

It may also be difficult to obtain true informed consent, due to the lower education and literacy levels common among OSY.

Assuring confidentiality

Confidentiality protects subjects from the negative consequences that may arise from participating in a study or survey. Be aware of any of your country's laws that may complicate participation. These may include:

- laws prohibiting working under a certain age
- laws prohibiting sex work or sex work under a certain age
- laws prohibiting drug use
- laws requiring reporting of individuals with HIV infection.

People asked to participate in a survey or study should understand potential threats to their anonymity. They should also understand the steps that the investigators will take to minimise them. Explaining these issues to them is part of the *informed consent* process.

Steps you can take to minimise threats to anonymity may include:

- conducting anonymous interviews with OSY in private settings
- collecting no identifying information about OSY
- limiting access to all information study data to authorised study personnel only
- keeping study documents in a locked, limited-access room.
- having all staff sign confidentiality forms and undergo training in research ethics.

Working with adolescents

Different countries have different laws and standards about when an adolescent can participate in research involving sexual behaviours. There are also different laws regarding the age of majority and when parental consent is required. Familiarise yourself with these laws in your country as part of your initial formative research efforts. Generally, surveillance tries to minimise the number of participants in the age range of 15-18 years, and avoids including those less than 15 years. If it is necessary to include children under the age of 15 years, special guidance on research with children should be sought.

Emancipation of minors is a process that occurs when a court (or another body given that authority) declares that someone who is still a minor is nevertheless to have the legal rights of an adult and to be free of any authority from their parent or other legal guardian. Each country has its own laws regarding the emancipation of minors, and many countries deem a minor to be automatically emancipated if they marry. It may be necessary to check your country's laws regarding parental consent and the age of majority, as some OSY may be considered minors, and obtaining consent from their parents may be difficult.

The World Medical Association has developed the Declaration of Helsinki as a statement of ethical principles to provide guidance to persons participating in research involving human subjects. The Declaration of Helsinki provides ethical guidance for research activities involving minors. Further information is available at: http://www.wma.net/e/policy/b3.htm.

Summary

Out-of-school youth (OSY) include diverse sub-populations, including street children, child labourers, adolescent SWs, married adolescents, and child soldiers. As people between the ages of 15 and 24 years are the fastest growing group of new HIV infections, it is crucial to identify and track high-risk groups within this population. Depending on the organisation and accessibility of OSY in your area, different sampling methods may be more or less feasible. Additionally, appropriate behavioural indicators will vary depending on the situation and sub-populations of OSY in your area. You should be aware that different countries will have different laws and standards about when an adolescent can participate in research involving sexual behaviours, and when parental consent is required. If you plan to include children under the age of 15 years in your surveillance activities, you should seek special guidance on research with children.

NOTES

Exercises

Warm-up review

Take a few minutes now to look back at your answers for the warm-up questions at the beginning of this unit. Make any changes you want to make. We will discuss the questions and answers in a few minutes.

Small group discussion

Get into small groups to discuss these questions.

1. Does your country conduct behavioural and/or sero-surveillance of OSY?

2. In your country, who are the gatekeepers of this population?

3. In your country, what methods have been used to sample OSY?

4. In your country, what behavioural and biological measures have been used when conducting surveillance of OSY?

5. In the past five years, has the prevalence of HIV among OSY increased, decreased, or remained about the same?

Apply what you have learned/ case study

Conducting Behavioural Surveillance among Street Youth in Great Gorge, Globa

Part 1: Collecting information to plan surveillance activities

Great Gorge, with a total population of 5 million, is the economic and administrative capital of Globa.

In 2005, data from STI surveillance found that number of new diagnoses of Chlamydia among teens had doubled since 2000. Alarmed by these results, the Globan Ministry of Health developed a package of youth-targeted, evidence-based interventions to reduce HIV, including a national multi-media prevention campaign composed of billboards, leaflets, and radio and television broadcasts.

The Commissioner of Public Health for the Great Gorge Metropolitan area is alarmed by recent NGO reports that an increasing number of street youth, some as young as 15 years, are presenting at urban public health centres with STIs and symptomatic HIV infection. She worries that the interventions and media campaign might not be reaching the street youth and/or have not been effective in preventing HIV infection among these youth.

The Great Gorge Commissioner of Public Health directs the HIV Programme Manager to undertake a survey of street youth in Great Gorge to determine their sexual and injecting behaviours and to assess whether they have been exposed to the multi-media HIV prevention campaign. She holds a meeting with her team of epidemiologists and social workers to plan for the survey.

1. What information is required for planning the survey?

2. How will the Great Gorge HIV team obtain this information?

Part 2: Building key alliances with community networks involved with street youth

Prior to conducting the survey, the HIV team need to conduct formative assessment activities (such as ethnographic mapping) to decide who they want to survey, where these youth can be found, what questions to ask, and the ethical considerations of undertaking such a survey.

To obtain background information for designing a behavioural survey, the HIV team review several documents, including peer-reviewed articles, government reports, NGO reports, clinic records of the public and private clinics, and reports from the police department. Several key informants are contacted, including current and former street youth, railway station employees, police, NGO managers, and outreach health workers. The HIV team collect information on the locations where street youth sleep, work, and congregate and the public health services and NGOs operating in the area.

Through discussions with current and former street youth, the HIV team realise that the street youth are highly distrustful of outsiders, including researchers, and are fearful that involvement in research activities may lead to the destruction of their illegal squatter settlements and/or their arrest. The team decide that in order to access street youth, they must enlist support of gatekeepers, whom the street youth know and trust.

1. Who are important gatekeepers who can help the HIV team gain access to the street youth in Great Gorge?

2. What actions can the HIV team take to address the street youths distrust?

Part 3. Choosing approaches to behavioural survey

Through discussions with current and former street youth and managers of NGOs working with street youth, the HIV team learn that many of the street youth are organised in cliques (or groups), with certain cliques (or groups) living and working as a team. Using the contacts of the current and former street youth the HIV team meet with "senior" street youth who have influence among other street youth.

The HIV team also meet with NGO managers and the police in the area.

A briefing meeting is organised, at which the HIV programme manager informs the stakeholders about the need for and purpose of the behavioural survey. The expected outcome of the survey is explained to the audience.

With a verbal assurance of the cooperation of the stakeholders and assurance from the police not to arrest street youth participating in the survey or destroy their settlements, the HIV team are now able to move to the next step.

3. What sampling methods are appropriate for sampling street youth in Great Gorge?

4. What are the advantages and disadvantages of each approach?

5. How would the HIV team construct their sampling frame?

6. What kinds of incentives should the HIV team offer the street youth who participate in the survey?

Part 4. Collecting behavioural data

The HIV team consider their sampling options and determine that they could:

1) conduct targeted sampling
2) conduct TLS at the locations where street youth congregate
3) use snowball sampling
4) conduct RDS.

The team weigh the pros and cons of each approach. The team consider the following:

- Targeted sampling requires knowing the venues and then developing a sampling frame based on quotas, but is not a probability-based sampling method.
- Snowball sampling is easier to conduct and requires less recourse than TLS or RDS, because it does not require a sampling frame. Like targeted sampling, snowball sampling is not a probability-based sampling method.
- RDS and TLS are probability-based sampling methods that have more external validity than either snowball sampling or targeted sampling.

Given that street youth sleep, work, and congregate in identifiable and accessible locations, the availability of adequate resources, and the strengths of TLS as a probability sampling method, the team decide to conduct TLS to obtain a representative sample of street youth in Great Gorge.

The HIV team construct a list of sites where street youth live, work, and meet. These sites include squatter settlements where many street youth sleep, bus stations, train stations, busy intersections, and markets where street youth beg and hock goods, and parks where street youth congregate. The team then visit these venues and count the number of street youth present at the venues at specific times. The team statistician determined that the HIV team need to survey a total of 600 street youth; thus, the HIV team decide to use a two-stage cluster sampling design. In stage I, 20 locations are randomly selected using a list of random numbers. In stage II, a fixed number of 30 street youth are selected from each selected site at a randomly selected three-hour time period on a randomly selected day of the week.

Although the HIV team discuss providing financial incentives, for ethical reasons they decide to give a packet of biscuits and a hot meal as the incentive to participate.

7. What behavioural variables should be collected?

Part 5. Results

At the randomly selected locations and times, trained interviewers explain the purpose of the study to the youth and obtain verbal consent. Confidentiality is assured. The interviews are conducted in privacy and in a non-coercive manner. Personal identifiers are not collected.

Trained interviewers administer a pre-tested, semi-structured questionnaire to recruited youth in order to assess HIV risk behaviour, HIV-related knowledge, and exposure to interventions.

The questionnaire includes queries on demographics and the context of street life, including age, gender, household information, lifetime years on streets, literacy and educational information, including current school attendance, and highest grade completed. Participants are asked about lifetime history of sexual intercourse, age of first intercourse, frequency of condom use, if they had ever exchanged sex for money, if they had ever experienced any kind of sexual abuse in streets or in the home, and alcohol and illicit drug use. Youth are asked about the number of sexual partners they had in the previous year, whether they were diagnosed with any STIs, and whether they had any unprotected sex under influence of drugs or alcohol. HIV-related knowledge and information included items asking about any HIV testing history and whether they could correctly identify condom use as a means of preventing HIV transmission. To assess the youths' recognition and exposure to HIV prevention interventions, including the national mass-media prevention campaign, campaign logos and campaign audio recordings are presented to participants, along with control HIV/STI prevention logos and audio recordings. Participants are asked which logos they had previously seen and which audio recordings they had previously heard. Those surveyed are also asked about their health-seeking behaviour and the frequency with which they utilised public health centres.

Data are entered in a database, cleaned and analysed using the statistical software STATA. A summary of the results is presented to the Great Gorge Public Health Commissioner.

Although the study cannot afford to provide HIV or STI testing, referrals and vouchers for these services are offered to all street youth who participate in the survey.

Part 5. Results, continued

The survey produces the following results:

Demographics

- The sample included 600 street youth (480 boys and 120 girls).
- Median age of those who participated was 16 years (range 12-19).
- Boys were significantly older than girls (median age 17 vs. 14, $p<.01$).
- Girls were more likely in contact with their family than boys ($p<.05$).
- Most respondents lived on the street or in illegal squatter settlements.
- Only 6% (36) of respondents had electricity at the location where they spent the last night.
- 45% (267) of respondents were literate (50% of boys; 22.5% of girls).
- 5% of those surveyed reported having run away from home as a result of sexual or physical abuse in their home (with girls more frequently reporting this occurrence, $p<0.05$).
- 10 reported having run away from home because of a forced marriage (girls more frequently reported this occurrence, $p<0.05$).

Sexual behaviours

- A significantly higher proportion of boys (67%) than girls (30%) reported ever having had sexual intercourse ($p<.01$)
- Median age of sexual debut was 15 for boys and 13 for girls
- Females reported more sexual partners in the last year than males.
- 15% of female respondents reported having performed sex or sexual favours for money within the previous year, compared to only 4% of male respondents.
- An additional 10% of female respondents reported having exchanged sex for food or other goods, mostly with other street youth.
- 5% of male respondents reported having provided female street youth with food or protection in exchange for sex or sexual favours.
- 11% of female respondents reported having been raped while living on the streets.
- 26% of those who were sexually active reported history of condom use "in general," while 72% reported using a condom during most recent sexual intercourse

Drug use

- Alcohol was the substance most frequently used within the year among boys (85%) and girls (79%).
- Girls were less likely to report having used marijuana, inhalants and/or methamphetamines in the last year ($p<.05$).
- Injection drug use was reported by only two participants (1.2%), both male.

Part 5. Results, continued

HIV knowledge

- Nearly all respondents had heard about HIV/AIDS, but only 32% mentioned that consistent use of condoms could prevent transmission of HIV and other STIs.
- 56% of respondents believed that they would never get HIV.
- 11% of the participants reported having been tested for HIV; only one respondent reported that he/she was HIV-infected.

Exposure to interventions

- Only 12% of those surveyed had been exposed to the government's mass-media HIV prevention campaign.
- All those who had been exposed to it had heard the radio component of the campaign.
- Nearly all of the youth surveyed knew the locations of the public health centre that served street youth; yet only 10% reported having utilised these services.
- Fear of being arrested or "sent home" was the most commonly cited reason why street youth did not utilise public health services.

8. Based on the community survey, what are the main factors that put street youth at risk of transmitting and acquiring HIV?

9. What interventions should be initiated based on these results?

Part 7. Epilogue

Based on the community survey, street youth were highly at risk of acquiring and transmitting HIV; HIV-related knowledge was low; many female street youth had performed sex work and had been raped or abused; and many children had run away from home to escape abusive relationships or forced marriages. Injection drug use was low, although glue sniffing was common. Street youth did not utilise the public health centres, although they knew they existed. Urgent targeted interventions were needed to increase safe sex practises and HIV-knowledge among street youth in Great Gorge.

Based on these findings, the public health commissioner of Great Gorge directs the HIV programme manager to initiate the following interventions:

- design interventions specifically targeted at street youth
- engage peers and NGO outreach workers to educate street youth about HIV/STI transmission and prevention
- disseminate "best practises" to researchers and practitioners that have worked with street youth across different cities
- work with local police and public health centres to establish times when street youth can visit public health centres without fear of being arrested or persecuted.

NOTES

Module Summary

1. Sometimes referred to as "at-risk groups" or "*most at-risk populations*" (MARPs), members of high-risk groups are at increased risk of passing HIV on to others or of contracting HIV from others.

2. Populations at increased risk include *sex workers* (SWs), *injecting drug users* (IDUs), *men who have sex with men* (MSM), mobile populations, street children, *prisoners*, and *out-of-school youth* (OSY).

3. Populations at increased risk play a central role in the spread of HIV infection. At the beginning of an HIV epidemic, the first infections appear in these groups because they have more higher-risk behaviours. These behaviours include:
   - having sex without using a condom (*unprotected sex*) with multiple partners and/or having a large number of new partners
   - injecting drugs with shared needles.

4. Understanding the spread of HIV in high-risk groups is essential. Surveillance data can contribute to advocacy for improved care and treatment for MARPs and evaluate the success of HIV and STI control programmes.

5. The first step in planning HIV surveillance in high-risk populations is to gain an understanding of the populations. *Formative assessment* activities are conducted to identify key *indicators* to measure the diversity of the sub-populations and the geographic areas and venues where high-risk populations may be found in large numbers.

6. There are several conventional probability sampling methods that can be used for sampling MARPs. As many populations at increased risk are *hard-to-reach populations*, *respondent-driven sampling* (RDS) and *time-location sampling* (TLS) are ideally suited for surveys of high-risk groups.

7. RDS combines the methods of *snowball sampling* with a mathematical model in a way that weighs the sample to compensate for the non-random way it was collected. It is an experimental sampling method that does not require a sampling frame. It is especially good for finding hard-to-reach groups, which are small compared to the general population.

Module Summary, continued

8. TLS, which is also called time-venue, time-space or venue-day-time sampling, combines the methods of targeted sampling and *cluster sampling* in a way that produces a *probability sample*. TLS requires extensive *ethnographic mapping* to prepare a *sampling frame* that captures the variability in the time and location of behaviours and the number of group members.

9. The selection of indicators for surveying high-risk groups should be determined by your country's data needs. The formative assessment phase should be used to determine the local questions of greatest relevance to the epidemic in your area.

10. *Behavioural surveillance* indicators should measure behaviours that are essential to the spread of HIV and that are targeted by HIV prevention programmes, including:

    - behaviours that increase the chance that an uninfected person will come into contact with an infected person
    - behaviours that increase the chance that HIV will be transmitted if contact with an HIV-infected person occurs.

11. There are a number of choices to make about which biological measures to use in surveys of high-risk groups. Choices include HIV, which is almost always included, and other infections that are markers of behaviours associated with HIV transmission.

    - Rates of acute STIs are often used as a proxy for the presence of sexual behaviours that could result in the transmission of HIV.
    - Groups at high risk for parenterally acquiring HIV, such as IDUs, have increased risk of other blood-borne infections. *Hepatitis C virus* (HCV) is the blood-borne infection most typically measured.

12. Many high-risk groups are marginalised, and sometimes their behaviour is illegal. It is important to understand your country's laws regarding sex work, injection drug use, and the required reporting of individuals with HIV infection, as these laws may complicate the participation of some at-risk populations.

NOTES

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Appendix B, Glossary and Acronyms

ACASI: Acronym for 'audio computerised assisted survey instruments.'

Accuracy: Refers to how well the sample reflects (nearest to the truth) the study population.

Acquired immunodeficiency syndrome (AIDS): See Advanced HIV infection.

Active infection: An infection that is currently producing symptoms (disease) or in which the organism that causes disease is reproducing.

Active surveillance: A system in which the organisation conducting surveillance initiates procedures to obtain reports. Example: making telephone calls or visits to health facilities to obtain information.

Adherence: The extent to which a patient takes his/her medication according to the prescribed schedule (also referred to as 'compliance').

Advanced HIV disease reporting: The systematic and standardized ongoing reporting of persons diagnosed with advanced HIV disease (clinical stage 3 or 4 and/or CD4 counts ≤350.

Advanced HIV infection: (*also* Advanced HIV disease) The late stage of HIV infection that includes development of one or more opportunistic illnesses (illnesses that occur because of low levels of CD4 lymphocytes, or immunodeficiency). Advanced HIV infection (disease) is the term now used for AIDS in updated WHO Guidelines.

Aetiologic case reporting: A surveillance system in which a laboratory test has confirmed the presence of the pathogen.

Aetiological: Refers to the causes of disease. Also known as 'aetiologic.'

Agent: A factor, such as a micro-organism, chemical substance, or form of radiation, whose presence is essential for the occurrence of a disease.

Aggregate case reporting: A single form summarises all of the patients who were diagnosed with the condition at certain sites in a given time period.

AIDS: Acronym for 'Acquired Immunodeficiency Syndrome.'

AIDS case reporting: The identification and reporting of persons meeting the AIDS case definition to permit public health authorities to track the disease over time. Also known as 'AIDS case surveillance.'

AIDS case surveillance: The identification and reporting of persons meeting the AIDS case definition to permit public health authorities to track the disease over time. Also known as 'AIDS case reporting.'

AIDS-defining illness: Any of a series of health conditions that are considered, in isolation, or in combination with others, to be indicative of the development of AIDS. These conditions result from low levels of CD4 lymphocytes which are destroyed by HIV.

AIDS Indicator Survey (AIS): A standardized tool to obtain indicators for effective monitoring of national HIV/AIDS programs. The protocols will help us provide, in a timely fashion and at a reasonable cost, the information required for meeting HIV/AIDS program reporting requirements.

Algorithm: Step-by-step procedure for decision-making; a recipe for achieving a specific goal.

Aliquot: A portion of a sample; for example, an aliquot of a 100 millilitre sample of blood might be a 5 millilitre portion of that sample.

Alliances: Partnerships created to assist with formative assessment. These partnerships differ based on the type of most-at-risk group being sampled, but usually include gatekeepers, governmental or non-governmental organisations, influential members of the target group, advocates, and physicians and others who provide health care to the target group.

Anonymous: Having no known name or identity. Removing all personally identifying information from a sample that will be tested for HIV, for example, in order to protect the patient's identity.

Anti-microbial resistance: The ability of an organism to avoid destruction or deactivation typically caused by drugs or chemicals designed to do so.

Antibiotic medicines: Drugs that kill or inhibit the growth of bacteria.

Antibodies: Molecules in the blood or secretory fluids that tag, destroy, or neutralise bacteria, viruses, or other harmful toxins.

Antimicrobial agents: An agent that kills or inhibits microbial growth. 'See Antibiotic medicines.'

Antiretroviral drugs: Drugs used to fight infections caused by retroviruses, such as Advanced HIV Disease.

Antiretroviral drug resistance: Resistance to one or more antiretroviral drugs. Antiretroviral drug resistance is one of the more common reasons for therapeutic failure in the treatment of HIV.

Antiretroviral therapy (ART): Treatment with drugs that inhibit the ability of HIV to multiply in the body.

Area map: A map used as a graph showing variables by geographic location.

Artefact: An inaccurate observation, effect or result caused by experimental error.

Asymptomatic: Without symptoms.

At-risk groups: Groups of people that are at increased risk for passing HIV on to others or for being infected by others.

B-lymphocytes: Also known as 'B-cells.' Blood cells of the immune system involved in the production of antibodies. In persons living with AIDS, the functional ability of both the B and the T lymphocytes is damaged, with the T lymphocytes being the principal site of infection by HIV.

Bacterial vaginosis: A chronic inflammation of the vagina caused by the bacterium *Gardnerella vaginalis*.

Bangui: The initial WHO AIDS surveillance case definition, developed to provide case definition of AIDS for use in countries where testing for HIV antibodies was not available.

Bar chart: A visual display of the size of the different categories of a variable. Each category or value of the variable is represented by a bar (or column). The Y-axis represents frequency. The X-axis represents different classes.

BED assay: A simple enzyme immunoassay (EIA) that can be used for detecting recent HIV-1 infection (within the last 160 days). It uses a branched peptide that includes sequences from HIV sub-types B, E and D, and allows detection of HIV-specific antibodies among various sub-types.

BED capture-EIA test: This test detects an antibody to a small HIV protein, gp41. It was first tested in HIV types B, E and D, hence its name BED.

Behavioural surveillance: Surveys of HIV-related behaviour that involve asking a sample of people about their risk behaviours, such as their sexual and drug-injecting behaviour.

Beneficence: To promote the interest of the patient or participant. To balance the benefits and risks to people involved in surveys. These risks include physical harm, such as violence and psychological harm, such as social stigmatisation.

Bias: A systematic error in the sample selection and the collection or interpretation of data.

Biological surveillance: Surveillance that involves regular and repeated cross-sectional surveys, but collects biological samples that are tested for HIV and other related illnesses, such as sexually transmitted diseases and tuberculosis.

Bivariate analysis: One of the main types of behavioural surveillance analysis that is performed to determine whether one variable is related to the distribution of another. For example, there might be an association between a respondent's age (the explanatory variable) and their use of condoms (the outcome variable). Variables are associated if the value of one tells you something about the value of another. Statistical tests in bivariate analysis determine whether any observed difference reflects a true difference, or may be due to chance.

Body fluids: Any fluid produced by the human body, such as blood, urine, saliva, sputum, tears, semen, mother's milk, or vaginal secretions. Fluids that commonly transmit HIV are blood, semen, pre-ejaculate, vaginal fluids, and breast milk.

Bridging populations: Persons in high-risk sub-populations who interact with people of lower risk in the general population, making it more likely that the HIV epidemic shifts from concentrated to generalised.

BSS: Acronym for 'behavioural surveillance survey.'

***Candida albicans*:** The fungal causative agent of vulvovaginitis in women and inflammation of the penis and foreskin in men.

CAPI: Acronym for 'computer-assisted personal interview.'

Capture-recapture: A technique used to estimate numbers of persons in a target population. Two or more lists containing individuals in common can establish the number of individuals missing from both, thereby estimating the total population of interest.

Carrier: A person or animal without apparent disease who harbours a specific infectious agent and is capable of transmitting the agent to others.

Case: An individual in the population or sample with a particular disease of interest.

Case-based reporting: each person diagnosed with the disease is reported separately, as opposed to aggregate case reporting in which data from patients with the disease are combined.

Case-control study: A type of observational analytic study. Enrolment into the study is based on presence ('case') or absence ('control') of disease. Characteristics such as previous exposure are then compared between cases and controls. The purpose of case control studies is to identify factors that are associated with, or explain the occurrence of the specific disease or condition being studied.

Case definition: A set of standard criteria for deciding whether a person has a particular disease or health-related condition, by specifying clinical criteria and limitations on time, place and person.

Case fatality rate: The proportion of patients who become infected or develop a disease that dies as a result of that infection or disease.

Case reporting: A surveillance system in which persons who are identified as meeting the case definition are reported to public health authorities.

CASI: Acronym for 'computerised assisted survey instruments.'

Catchment population: A geographic area that is to be examined or surveyed. Can refer to the population served by a given clinic.

Categorical surveillance system: System that deals with reporting a single disease.

Categorical variable: Items that can be grouped into categories, such as marital status or occupation.

Cause of disease: A factor (characteristic, behaviour, etc.) that directly influences the occurrence of disease. A reduction of the factor in the population should lead to a reduction in the occurrence of disease.

CD4 count: A measure of the number of CD4 cells in a millilitre (mL) of blood. The CD4 count is one of the most useful indicators of the health of the immune system and a marker for the progression of HIV/AIDS.

CD4 receptors: Markers found on the surface of some body cells, including T-cells. These receptors are targets of HIV, and thus CD4+ cells are attacked by the virus.

Census sampling: Every unit, or case, is measured for the entire population. A de facto census allocates persons according to their location at the time of enumeration. A de jure census assigns persons according to their usual place of residence at the time of enumeration (Last).

Centers for Disease Control and Prevention (CDC): The US Department for Health and Human Services agency with the mission to promote health and quality of life by preventing and controlling disease, injury, and disability.

Chain referral sample: Any sampling method wherein participants refer other potential participants for inclusion in the sample. There are several types of chain referral sampling methods, most of which are non-probability samples. Examples of chain referrals include RDS, network sampling, random walk and snowball sampling.

Chancroid: An acute, sexually transmitted, infectious disease of the genitalia caused by the bacteria *Haemophilus ducreyi*. The infection produces a genital ulcer that may facilitate the transmission of HIV.

Characteristic: A definable or measurable feature of a process, product, or variable.

Chlamydia trachomatis: The most common sexually transmitted bacterial species of the genus Chlamydia that infects the reproductive system. Chlamydia infection causes infection of the cervix of women and the urethra of men and is frequently asymptomatic. If left untreated, it can cause sterility in women.

Clinic-based surveys: Surveys that use samples that have been selected in clinical facilities, such as STI or drug treatment clinics. The most common type of the clinic-based surveys that are done using biological markers, such as HIV infection, is clinic-based sentinel sero-surveillance.

Cluster: Any aggregate of the population of interest (for example, departments, villages, health facilities).

Cluster sampling: The population of interest is broken into groups or clusters and a sample of clusters is randomly selected (Levy & Lemeshow).

Clustered bar chart: A bar chart in which the columns are presented as clusters of sub-groups. Also known as 'stacked bar chart.'

Code: A unique identification for a specimen. It may or may not be linked to any personal identifying information.

Cohort analysis: Analysis that involves following groups of subjects over time.

Cohort studies: Cohort studies follow a group of initially uninfected people over time, and test them repeatedly. Cohort studies follow a well-defined group of people who have had a common experience or exposure, who are then followed up for the incidence of new diseases or events, as in a cohort or prospective study tested repeatedly over a long period of time.

Community advisory board: Members of the community who offer input into study design and local procedures. CAB members include community activists and/or professionals associated with HIV/AIDS prevention and services delivery. Some CAB members are trial participants.

Community-based surveys: Surveys that use samples that have been selected from non-clinical settings. They often include most-at-risk populations, such as sex workers or truck drivers, who are not included in clinic-based surveys. As with clinic-based surveys, the most common type of community-based survey is called 'repeated cross-sectional community-based sentinel sero-surveillance.'

Community sites: Locations in the community, such as households or brothels.

Completeness of data elements: The extent to which the information requested in the case report form is provided.

Completeness of reporting: One of several attributes of a surveillance system. The term refers to the proportion of cases that were reported. Completeness of reporting is also referred to as the sensitivity of the surveillance system and is determined by using an alternative (and thorough) method of identifying cases of the disease and then dividing the number of cases reported by the total number of cases identified. Completeness is often reported as a percentage.

Compulsory testing: Testing that is required of all individuals in a population to be surveyed. For example, requiring HIV tests to be done on all members of a prison population.

Concentrated HIV epidemic: The epidemic state in which HIV has spread to a high level in a defined subpopulation but is not well established in the general population. HIV prevalence is consistently >5% in at least one defined subpopulation and is <1% in pregnant women in urban areas.

Confidence interval: The compound interval with a given probability, for example, 95% that the true value of a variable such as mean, proportion, or rate is contained within the limits. Also known as 'confidence limits.'

Confidence limits: See 'confidence interval.'

Confidentiality: Protecting information that concerns a study participant or patient from release to those who do not need to have the information.

Consecutive sampling: This sampling method consists of sampling every patient who meets the inclusion criteria until the required sample size is obtained or the survey period is over. While this method is not strictly a probability sample, it is easier to use and offers less occasion for sampling bias.

Contact: Exposure to a source of an infection, or a person so exposed.

Contagious: The characteristic of an organism or person that renders it capable of being transmitted from one person to another by contact or close proximity.

Continuous variable: Items that occur in a numerical order, such as height or age.

Convenience sampling: The selection of entities from a population based on accessibility and availability. Available participants may be people on the street, patients

in a hospital or employees in an agency. This type of sampling does not generally represent the population of interest and is best used in the exploratory stage of research.

Core data elements: Information about a patient that must be collected during a survey.

Cotrimoxazole preventative therapy (CPT): Administering cotrimoxazole prophylaxis to prevent opportunistic infections among HIV- infected patients.

Cotrimoxazole prophylaxis: A combination of two anti-infection drugs, sulfamethoxazole and trimethoprim, used to prevent opportunistic infections in patients with HIV.

Coupon: Used in RDS studies to provide incentives to participants. Coupons in RDS can be used both to track participation for reimbursements and to link the recruiters to the recruits. Other methods may use coupons to encourage participation, much like the advertisements placed in popular clubs or bars. Some coupons may have two parts that can be easily separated. One part of the coupon serves as the referral coupon, which the recruiter uses to recruit a peer into the study. The other part of the coupon serves as the payment coupon. It is kept by the recruiter and he or she will use it to claim an incentive for having recruited a peer into the study. Both parts of the coupon have the unique identification number of the recruitee printed on them. The dual system eliminates the need to collect names for incentive collection.

Coupon rejecters: People who are offered a coupon by a recruiter, but decline to take it.

Cross-sectional survey: A survey that is conducted over a given period of time, such as during a single year, rather than over an extended period of time.

Cruising area: Cruising areas are public space, such as parks, public restrooms, bath houses, dance clubs and railway stations where MSM meet, congregate and arrange and/or engage in sexual activity.

Cryolabel: Labels designed to adhere during freezer storage.

Cryovial: A vial that is designed to be stored in a freezer.

CSW: Acronym for ‘commercial sex worker.’

DALYs: See ‘disability-adjusted life years.’

Database: A computer programme that stores the variables for each patient in the survey sample or surveillance system.

Data dictionary: Electronic files that describe the basic organisation of a project or database. They contain all of the rules that guide data entry.

Data entry: The process of entering paper records into a computer database

Data entry screens: The forms on the computer screen into which a data entry clerk enters the data.

Data synthesis: See 'triangulation.'

Definitive diagnosis: A diagnosis based on laboratory or other tests specifically designed for diagnosis and considered authoritative.

Demographic Health Survey: National household surveys that provide data for a wide range of monitoring and impact evaluation on topics including HIV prevalence and attitudes and beliefs about HIV/AIDS.

Demographic information: The 'person' characteristics of epidemiology (usually collected with "place" and "time") – age, sex, race and occupation – used to characterise the populations at risk.

Denominator: The population (or population experience, as in person-years, etc.) at risk in the calculation of a proportion or rate. The denominator is the lower portion of a fraction used to calculate a rate or ratio.

Dependent variable: In a statistical analysis, the outcome variable(s) or the variable(s) whose values are a function of other variable(s).

Descriptive statistics: Used to describe the basic features of the data, they provide simple summaries about the sample and the measures.

DHS: Acronym for 'demographic and health surveys.'

Dichotomous variable: A special type of nominal variable that has only two categories, such as male/female.

Differential recruitment: Recruiters successfully bring recruits in at different rates.

Direct transmission: The immediate transfer of an agent from a reservoir to a susceptible host by direct contact or droplet spread.

Disaggregated data: Data which is divided up according to different variables, to provide a more detailed analysis.

Disability-adjusted life years (DALYs): A measure of burden of disease in a population obtained by combining 'years of life lost' and 'years lived with disability.'

Disease burden: The size of a health problem in an area, as measured by cost, mortality, morbidity or other indicators.

Disease registry: The file of data that contains reported diseases.

Disease reporting: The process by which notifiable diseases are reported to the health authority.

Disinhibition: Poor decision-making when considering risk-taking behaviours.

Distribution: The frequency and pattern of health-related characteristics and events in a population. In statistics, the observed or theoretical frequency of values of a variable.

Double-entered: Entered twice, to avoid mistakes by identifying and correcting discrepancies.

Double Y-scale: On a graph, two Y-axes, one on the vertical left for data with large values and one on the vertical right for data with smaller values.

Dysuria: Painful, frequent or difficult urination.

EIA: See 'enzyme-linked immunoassay.'

ELISA: See 'enzyme-linked immunosorbent assay.'

Emic: Refers to accounts, descriptions, and analyses expressed in terms of the concepts and categories regarded as meaningful and appropriate by the members of the population of interest.

Endemic disease: The constant presence of a disease or infectious agent within a given geographic area or population group; may also refer to the usual prevalence of a given disease within such area or group.

Enumeration units: The sampling units from the final stage of a multistage sampling design. See 'Listing units.'

Enzyme immunoassay (EIA): A type of test that identifies antibodies to an organism such as HIV. EIAs rely on a primary antigen-antibody interaction and can use whole viral lysate of HIV or one or more antigens from the virus.

Enzyme-linked immunosorbent assay (ELISA): A type of enzyme immunoassay (EIA) to determine the presence of antibodies to an infectious agent such as HIV in the blood or oral fluids.

Epidemic: The occurrence of a disease (or other health-related event) at a greater than expected level of increase to a baseline. For example, the high prevalence of HIV found in many parts of the world today, including sub-Saharan Africa, Latin America and South and Southeast Asia.

Epidemic state: The prevalence the epidemic has reached in a country or region. Can be low-level, concentrated, or generalized within a sub-population or within the general population.

Epidemiology: The study of the distribution and determinants of the frequency of health-related states or events in specified populations, and the application of this study to the control of health problems.

Epi Info™: Freely distributed epidemiological software available on the CDC website (www.cdc.gov/epiinfo).

Equilibrium: In RDS, the point in the recruitment process where a variable is not expected to change by more than 2% with each successive wave.

Ethnographic assessments: Ethnographic assessments are written analyses of the cultural practices, beliefs and behaviours of a particular culture, network or sub-group.

Ethnographic mapping: Collecting information on the geographic location, temporal movement of and interactions among members of the study population.

Etic: Refers to accounts, descriptions and analyses expressed in terms of the concepts and categories regarded as meaningful and appropriate by the community of scientific observers.

Exclusion criteria: Characteristics of patients who should be excluded from the sample, but who would otherwise be eligible.

Experimental study: A study in which the investigator specifies the exposure category for each individual (clinical trial) or community (community trial), then follows the individuals or community to detect the effects of the exposure.

External validity: The ability to make inferences from the study sample to the population of interest.

Factor: An intrinsic factor (age, race, sex, behaviours, etc.) which influences an individual's exposure, susceptibility, or response to a causative agent

False negatives: Test results that are negative when the patient actually has the disease that is being tested for.

False positives: Test results that are positive when the patient does not actually have the disease that is being tested for.

Female sex workers: Females who engage in sex work, or the exchange of sex for money, which includes many practises and occurs in a variety of settings. These may

include ‘direct’ or ‘formal’ sex workers, who are sometimes included in registries and often found in brothels, and ‘indirect’ or ‘casual’ sex workers, who do not engage in sex work full time and are unlikely to be included in registries.

Filter paper: Porous paper on which samples can be placed.

Focus groups: A group setting in which people are asked by a facilitator about their views about a topic. Participants are free to talk with other group members as well as the facilitator. Focus groups allow interviewers to study people in a more natural setting than they can in a one-to-one interview.

Formative assessment (or research): Research conducted before the study begins. Researchers use qualitative methods, such as focus groups, in-depth interviews, mapping or observations of the target population and the individuals who work with them to ensure that the research team sufficiently understands the community.

GAP: Acronym for the CDC’s ‘Global AIDS Program.’

Gatekeepers: Persons who can provide access to a high-risk population. Examples are a brothel owner who can provide access to female sex workers, or a prison warden who can provide access to prisoners.

General population surveillance: Surveillance that measures HIV risk behaviours in a sample of people selected to represent the people living in a region or nation. The surveillance can be restricted to certain ages (for example, young people aged 15-24) or genders.

Generalisability: The results from the sample are the same as the results we would have obtained had we tested every person in the study population (that is, the results from the sample are generalisable to the study population).

Generalised HIV epidemic: The epidemic state in which HIV is firmly established in the general population. HIV prevalence is consistently >1% in pregnant women.

Genital discharge syndrome: This syndrome includes infections due to *N. gonorrhoea*, and *C. trachomatis*.

Genital ulcer syndrome: Genital lesions due to *T. pallidum, H. ducreyi*, HSV, *C. trachomatis* or *C. granulomatis*.

Geographical Information System (GIS): System of hardware, software.
Gigolo: Male sex workers who identify as straight. They tend to have foreign clients and engage in male-male sexual activity.

Glycoprotein (HIV): Proteins on the surface of the HIV virus that bind to CD4 receptors on target cells.and procedures designed for integrated storing, management, manipulation,

analysing, modelling and display of spatially referenced data for solving planningand management problems.

Gonorrhoea: An infection caused by *Neisseria gonorrhoeae* bacteria. Although gonorrhoea is considered primarily a sexually transmitted infection, it can also be transmitted to newborns during the birth process.

Gram-negative: Bacteria that do not absorb the stain during the process of Gram staining.

Gram-positive: Bacteria that do absorb the stain during the process of Gram staining.

Gram stain: A laboratory method of staining microscopic slides of organisms in order to identify and classify the various types of bacteria. Bacteria are classified as either Gram-negative (does not absorb the stain) or Gram-positive (absorbs the stain).

Graph: A diagram that shows a series of one or more points, lines, line segments, curves or areas, representing variations of a variable in comparison with variations of one or more other variables.

Grey literature: Material that is not published in easily accessible journals or databases. Besides programme evaluations, government surveillance reports and programme planning documents mentioned earlier, it includes the abstracts of research presented at conferences, and unpublished theses and dissertations.

***Haemophilus ducreyi*:** The causative agent of chancroid. See ‘chancroid.’

Health indicator: A measure that reflects, or indicates, the state of health of persons in a defined population; for example, the infant mortality rate.

Health information system: A combination of health statistics from various sources, used to derive information about health status, healthcare, provision and use of services, and impact on health.

Health-seeking behaviour: The actions individuals or populations take to care for their health, for example, attending a clinic or district hospital when they feel ill.

Hard-to-reach populations (HTRP): Groups of people linked by behaviours, socioeconomic situations or societal structures, who for various reasons (e.g. law, stigma) refrain from involvement in the legal economy and other aspects of the majority social institutions. Includes but is not limited to: IDUs, MSM, CSW and undocumented migrants.

Hepatitis B virus (HBV): The causative agent of hepatitis B. The virus is transmitted by sexual contact, the use of contaminated needles and instruments and by contaminated serum in blood transfusion. The infection may be severe and result in prolonged illness, destruction of liver cells, cirrhosis or death.

Hepatitis C virus (HCV): The causative agent of hepatitis C. This virus is transmitted largely by the use of contaminated needles and instruments and by blood transfusions. The disease progresses to chronic hepatitis in up to 50% of the patients acutely infected.

Herpes simplex virus 1 (HSV-1): A virus that causes cold sores or fever blisters on the mouth or around the eyes, and can be transmitted to the genital region.

Herpes simplex virus 2 (HSV-2): A virus causing painful sores of the anus or genitals. While this is a sexually transmitted infection, it may be transmitted to a newborn child during birth from an infected mother.

Herpes viruses: A group of viruses that includes herpes simplex type 1 (HSV-1), herpes simplex type 2 (HSV-2), cytomegalovirus (CMV), Epstein-Barr virus (EBV), varicella zoster virus (VZV), human herpes virus type 6 (HHV-6), and HHV-8, a herpes virus associated with Kaposi's sarcoma.

Highly active antiretroviral therapy (HAART): The use of at least three ARV drugs in combination to suppress viral replication and progression of HIV disease by reducing the viral load to undetectable levels.

High-risk behaviours: Behaviours that increase the risk that a person will contract a disease.

High-risk group: A group in the community with an elevated risk of disease, often because group members engage in some form of risky behaviour.

High-risk group surveillance: Surveillance that measures HIV risk behaviours in groups whose behaviours, occupations or lifestyles could expose them to higher risk of acquiring and transmitting HIV than the rest of the population. These groups are often important in establishing, accelerating or sustaining the HIV epidemic.

High-risk heterosexuals (HRH): Includes but is not limited to: mobile populations, uniformed personnel and sex partners of other MARPs.

Histogram: A graph that represents a frequency distribution by means of rectangles whose widths represent class intervals and whose areas represent corresponding frequencies.

HIV: See 'Human Immunodeficiency Virus.'

HIV-1: A type of HIV with slight genetic variations from HIV-2. More easily transmitted than HIV-2.

HIV-2: A type of HIV with slight genetic variations from HIV-1. Less easily transmitted than HIV-1.

HIV case reporting: the systematic, standardized, ongoing collection of reports of persons diagnosed with HIV infection (clinical stages 1-4) and/or advanced HIV disease (clinical stages 3 and 4).

HIV clinical stages: In these modules, a classification by WHO of HIV disease on the basis of clinical manifestations that can be recognized and treated by clinicians in diverse settings, including resource-constrained settings. In order of severity, starting with the lowest, the stages are:

Stage 1: Often asymptomatic or with swollen glands
Stage 2: Symptoms, including moderate weight loss and respiratory infections
Stage 3: More severe symptoms, including extreme weight loss and severe bacterial infections. Called advanced HIV disease.
Stage 4: End-stage HIV infection (AIDS), with manifestations such as wasting syndrome, tuberculosis, lymphoma. Called advanced HIV disease.

HIV-negative: Showing no evidence of infection with HIV (for example, absence of antibodies against HIV) in a blood or tissue test.

HIV-positive: Showing indications of infection with HIV (for example, presence of antibodies against HIV) based on a test of blood or tissue.

HIV sub-types: Distinct lineages of HIV that contain genetic differences.

HIV viral suppression: Lowering the level of HIV RNA in plasma, below the threshold of detection.

Homophily: In RDS, a measure of the tendency of people to connect to other people like themselves.

HSV-2: see herpes simplex virus 2.

Human immunodeficiency virus (HIV): A retrovirus that causes AIDS by infecting T-cells of the immune system.

Human papilloma virus (HPV): A causative agent of genital warts.

IDSR: See ‘Integrated disease surveillance and response.’

IDU: Acronym for ‘injection (injecting or intravenous) drug user.’

Immune response: The activity of the immune system against foreign substances such as infectious agents including bacteria and viruses.

Immune system: The body's complicated natural defence against disruption caused by invading foreign agents (for example, microbes or viruses).

Immunodeficient: A situation in which a patient's health is compromised because his/her immune system is insufficient to ward off infections, thus making the person susceptible to certain diseases that they would not ordinarily develop.

Immunology: The science of the system of the body that fights infections.

Impact evaluation: An evaluation of a programme that determines what the impact of the programme is, as opposed to 'process evaluation.'

Impact indicators: A standardised set of indicators developed by UNAIDS to help monitor HIV prevalence in particular populations.

Incentive: A reward or reimbursement given to participants in a study. In RDS surveys, there are typically two levels of incentive: primary incentive and secondary incentive. A participant receives the primary incentive for enrolling in the study and completing an interview. The same participant receives secondary incentive(s) for recruiting his or her peers into the study. Incentives are not absolutely necessary in every situation and should be determined during formative research.

Incidence: A measure of the frequency with which an event, such as a new case of illness, occurs in a population over a period of time. The denominator is the population at risk; the numerator is the number of new cases occurring during a given time period.

Inclusion criteria: Characteristics required in study participants, in order to be considered for the sample.

Incubation period: A period of sub-clinical or unapparent pathologic changes following exposure, ending with the development of the infection.

Independent variable: An exposure, risk factor, or other characteristic being observed or measured that is hypothesised to influence the outcome (that is, the dependent variable).

Indicators: Specific data that are gathered to measure how well a prevention or treatment programme is doing as well as define an aspect of behaviour that is key to the spread of HIV. Indicators provide a way to track changes in behaviours over time and provide a way to compare levels of risk behaviours between different population groups.

Indicator mutations: Genotypic mutations that best predict resistance to a specific antiretroviral agent.

Indirect transmission: The transmission of an agent carried from a reservoir to a susceptible host by suspended air particles or by animate (vector) or inanimate (vehicle) intermediaries.

Infectiousness: The ability of an organism to cause infection.

Infectivity: The proportion of persons exposed to a causative agent who become infected by an infectious disease.

Information bias: Error that results from people who have a disease being misclassified as not having the disease.

Informed consent: The permission granted by a patient or a participant in a research study after he or she has received comprehensive information about a research study or medical procedure. Informed consent protects the person's freedom of choice and respects his or her autonomy with regard to decisions affecting his or her body and health.

In-group affiliation: In RDS, what homophily measures (group similarity based on ethnicity, age, socio-economic status and so forth).

Injection drug users (IDUs): Also called 'intravenous drug users,' they are persons who use or have used needles or syringes to inject drugs. Injection drug use is considered a high-risk behaviour.

Institutional review board (IRB): The committee designated to approve, monitor, and review biomedical and behavioral research involving humans with the aim of protecting the rights and welfare of research participants. Also known as ethics committee.

Institutional sampling: Individuals in an institution, such as prison, are sampled.

Integrated disease surveillance (IDS): An approach to surveillance in which communicable diseases are prioritised. Surveillance for all of the high-priority diseases is conducted in an integrated manner and is initiated at the district level. These diseases have a high potential for epidemic spread and can be controlled through public health measures.

Internal validity: The absence of substantial differences between groups at baseline; the absence of substantial difference of attrition rates between groups at follow-up.

Internally displaced persons (IDPs): IDPs are persons who have left their homes due to civil unrest or natural disasters, but have stayed in their homeland and have not sought sanctuary in another country.

Interval width: The range of certainty as to the true value of the calculated outcome value. For example, in the case of a 95% confidence interval, there is 95% certainty that the true outcome lies between the upper and lower bound of the interval. Statistically, this interval is equal to two standard deviations on either side of the calculated outcome value.

Interviewer error: Problems stemming from the actions and behaviours of the person doing the interview.

Intradermally: Injected into the layers of the skin.

Intramuscularly: Injected into a muscle.

Intravenously: Injected into a vein.

Involuntary migrants: Involuntary migrants include persons who have migrated away or have been displaced from their home countries due to an established or well-founded fear of persecution, or have been moved as a result of deception or coercion.

Isolates: A population of bacteria or other cells that has been isolated and cultured.

Isoniazid prophylaxis: Giving isoniazid to individuals with latent Mycobacterium tuberculosis infection, in order to prevent the progression to active disease. Prophylaxis with isoniazid significantly reduces the incidence of tuberculosis in adults with HIV and a positive tuberculin skin test result.

Key informants: Members of the target group, who can often become informal assistants.

Kick-off meeting: A meeting you host for community members who may in turn become seeds for the RDS survey. The purpose of the meeting is to educate seeds on study goals and process, inform seeds of their importance to the success of the study and encourage the seeds to be enthusiastic.

***Klebsiella granulomatis*:** The bacterial causative agent of granuloma inguinale or donovanosis.

Laboratory-initiated reporting: A surveillance system in which the reports of cases come from clinical laboratories.

Laryngeal TB: Tuberculosis involving the larynx, producing ulceration of the vocal cords and elsewhere on the mucosa, and commonly attended by hoarseness, cough, pain on swallowing, and hemoptysis.

Latent period: A period of unapparent infection following exposure to a pathogen, ending with the onset of symptoms of chronic disease.

Lessons learned: Information from actual studies that will help you make decisions when planning your study.

Linked anonymous HIV testing: In linked anonymous testing, a person agrees to have an HIV test, but the specimen is labelled with a code without a name or identifiers that could reveal the person's identity. This method is voluntary and requires obtaining informed consent and making the test results available (with appropriate counselling) to the person tested.

Linked confidential HIV testing: In linked confidential testing, a person agrees to have an HIV test with the assurance that the test result will be kept confidential and only selected health-care providers may be informed. This method is voluntary and requires obtaining informed consent and discussing the test results with the person. Linked confidential testing also allows for the collection of more detailed demographic and risk-behaviour information.

Linking: Refers to whether a tested individual's names or identifying information is associated with his or her HIV test results.

Listing units: The sampling units from the final stage of a multistage sampling design. See enumeration units.

Log scale: In a graph, when the data covers a large range of values, they are presented on a logarithmic scale. This type of scale reduces data to a smaller range so that it is easier to work with.

Longitudinal surveillance: Surveillance over time during which patients' status can be updated. *Longitudinal databases* allow the update of patients records over time with, for example, start dates for care, disease progression, new information.

Low-level HIV epidemic: The epidemic state in which HIV has never spread to significant levels in any sub-population, although HIV infection may have existed for many years. HIV prevalence has not consistently exceeded 5% in any defined sub-population. This state suggests that networks of risk are rather diffuse or that the virus has only been recently introduced.

Lymphocytes: A type of white blood cell that is involved with fighting infections in the body. The T lymphocyte is the cell that HIV infects and destroys.

Macrophage cells: Tissue cell derived from monocytes that protect the body against infections.

Male sex workers: Males who engage in sex work, or the exchange of sex for money, which includes many practises and occurs in a variety of settings.

Mandatory testing: Testing that is required of a patient if he or she is to obtain certain services; for example, mandatory HIV testing of individuals who request marriage certificates.

Margin of error: An estimation of the extent to which a survey's reported percentages would vary if the same survey were taken multiple times.

Markov process: A mathematical theory that provides a probabilistic description of the state of a system at any future time. The Markov process is especially relevant to RDS

because of the nature of the recruitment process, whereby a chain of peers recruiting peers is monitored through a coupon mechanism.

Marriage pressure: Family pressure on sons to marry to provide stability for parents and the continuation of the family name as well as to avoid the stigma of a person being MSM.

MARP: Acronym for most-at-risk population, a group within the community with an elevated risk of disease, often because group members engage in some form of high-risk behaviour.

Masking: Describes the behaviour of reclusive respondents, people who do not want to be found.

Mean: The measure of central location commonly called the average. It is calculated by adding together all the individual values in a group of measurements and dividing by the number of values in the group.

Men who have sex with men (MSM): Men who have sex with men (MSM) are one of the highest risk groups in the Americas, Asia, Europe and Oceania. For the purposes of this manual, we also consider male sex workers, transvestites and transgendered persons (*hijra*) in the MSM category.

Microbe: A micro-organism, such as a bacteria or virus.

Microbicide: A chemical or other agent that destroys microbes.

MICS: See 'Multiple Indicator Cluster Survey.'

Migrants: see 'mobile populations'

Mobile populations: Refers collectively to groups of people who move from one place to another (migrants). They may move temporarily, seasonally, or permanently and for either voluntary or involuntary reasons.

Monitoring: Evaluating a programme's performance over time.

Monitoring and Evaluation (M&E): Collecting and analysing accurate and reliable information that can be used to improve programme performance and planning.

Monocyte: A type of white blood cell.

Morbidity: Any departure, subjective or objective, from a state of physiological or psychological well-being.

Mortality rate: A measure of the frequency of occurrence of death in a defined population during a specified interval of time.

Mortality rate, infant: A ratio expressing the number of deaths among children under one year of age reported during a given time period divided by the number of births reported during the same time period.

MSC: See 'multi-stage cluster sampling.'

MSM: Acronym for 'men who have sex with men.'

MSW: Acronym for 'male sex worker.'

MTCT: Acronym for 'mother-to-child transmission.' See 'perinatal transmission.'

Multi-stage cluster sampling (MSC): Two- or more- stage sampling. Final units from selected clusters may be randomly selected.

- Simple two-stage cluster sampling
- Probability proportional to size sampling (PPS) is used when all clusters do not have the equal probability of being selected in the sample. PPS is a class of unequal probability sampling in which the probability of a unit being sampled is proportional to the level of some known variable (Levy & Lemeshow).

Multivariate analysis: One of the main types of analysis conducted in behavioural surveillance that is performed to look at the influence of at least two variables on another variable. since relationships between variables are often complex and interwoven. Multivariate techniques can pinpoint the individual effects of several explanatory variables on an outcome variable, which may be related to each other.

Natural history of disease: The temporal course of disease.

Needs assessment: A systematic examination of the type, depth and scope of a problem.

Negative controls: Specimens known to be negative and used to ensure that a laboratory reagent is working properly prior to testing specimens from patients.

Negative predictive value: In HIV testing, the probability that a person with a negative test result is not infected. Also known as 'predictive value negative.'
***Neisseria gonnorrhoeae*:** The causative agent of gonorrhoea.

Network: This sampling method may be used for groups whose members are socially linked. Ego-centred network sampling is based on random, representative or any other form of quota sampling (Schensul). Full relational network sampling begins with identification of individuals (see 'seeds') who act as entry points to the network.

NGO: Acronym for 'non-governmental organisation.'

Nominal variable: Variables that represent discrete categories without a natural order, such as marital status.

Non-probability sampling: The sampling units are selected through a non-randomised process; therefore, the probability of selecting any sampling unit is not known.

Non-random mixing: The tendency of people to associate preferentially with others who are like themselves.

Non-vesicular genital ulcer disease: An STI syndrome characterised by ulcers and the absence of vesicles.

Notifiable disease: A disease for which law or regulation requires reporting to the health authority.

Numerator: The upper portion of a fraction. In a rate, the numerator is usually the number of people infected.

Operational definitions of target populations: Definitions that are operationally useful for sampling and fieldwork purposes. For example, a definition that clearly identifies what constitutes a sex worker, in terms of duration of selling sex, form of payment, type of venue where they work, etc.

Operations manual: A document that describes every step to be taken during the implementation of a survey or study. Ideally, it provides standard operational procedures for every foreseeable occurrence.

Opportunistic infections: Illnesses caused by various organisms infecting immunodepressed persons that usually do not cause disease in persons with healthy immune systems. Persons with advanced HIV infection (that is, AIDS) suffer opportunistic illnesses of the lungs, brain, eyes, and other organs. These illnesses are referred to as AIDS-defining illnesses or conditions.

Opt-in: A patient or participant agrees to be tested.

Opt-out: A patient or participant refuses to be tested.

Optical density: The intensity of colour as measured by a machine in an EIA HIV antibody test, indicating whether the patient's sample is HIV-positive.

Ordinal variable: Variables that have a natural order, such as level of education.

Over-sampling: A sample may obtain more members of a particular sub-group than their representation in the target population warrants. In some cases, over-sampling is carried

on purpose to learn more about a small sub-group, such as female injection drug users in communities that are predominantly male.

p24 antigen: A protein that appears in the serum of infected individuals approximately one week before HIV antibodies appear, or about 14 days after actual infection. In very large sero-surveys, persons who tested negative for HIV antibody can be retested for p24 antigen.

Pandemic: An epidemic occurring over a very wide geographic area (several countries or continents) and usually affecting a large proportion of the population. HIV is an example of a pandemic.

Parameter: The summary numerical description of variables about the target population.

Parenteral transmission: Transmission of an infectious agent through blood. Parenteral transmission of HIV can occur from the sharing of injection drug equipment, from transfusions with infected blood or blood products, or from needle stick injuries.

Participant observation: A qualitative research method in which direct observation is carried out over a period of time, and which is understood and accepted by the group being observed.

Participation bias: Error in results from a study that is due to differences in characteristics between those who participate in a survey and those who do not. For example, persons who already know they are HIV-infected may find testing unnecessary; those who suspect they are HIV-infected may decline testing in order to avoid stigma.

Partner concurrency: Having extensive sexual network connections to many persons at the same time, which increases the spread of HIV and STIs.

Passive surveillance: A system in which a health-care provider or worker notifies the health authority of any cases of these diseases, as opposed to ‘active surveillance.’

Pathogen: A biological agent that causes disease or illness to its host (for example, bacteria or virus).

Payment coupon: Kept by the recruiter. He/she will use it to claim an incentive for having recruited a peer into the study.

Perinatal transmission: Transmission of an infectious agent, such as HIV, from mother to baby before, during, or after the birth process. Also known as ‘vertical transmission’ or ‘mother-to-child transmission.’

Period prevalence: The amount a particular disease that is present in a population over a specified period of time.

Pie chart: A circular chart in which the size of each 'slice' is proportional to the frequency of each category of a variable. A pie chart compares subclasses or categories to the whole class or category using different coloured slices.

PLACE: See 'Priorities for local AIDS control efforts.'

PLWHA: Acronym for 'Persons living with HIV/AIDS.'

PMTCT: Acronym for 'prevention of mother-to-child transmission.'

Point estimate: The amount of a particular disease present in a population.

Point prevalence: Refers to prevalence at a single point in time. Also known as 'point incidence.'

Population: The total number of inhabitants of a given area or country. In sampling, the population may refer to the unit from which the sample is drawn, not necessarily the total population of people.

Population-based sero-survey: A type of sero-survey that uses a probability sample of a population defined by geographic boundaries, such as villages or provinces, in order to obtain a direct measure of HIV prevalence in a general population.

Population sub-group: A group within a population that share certain characteristics or behaviours.

Positive controls: Specimens known to be positive, as used in proficiency testing.

Positive predictive value: The probability that a person with a positive test result is infected; in surveillance this refers to the proportion of cases reported by a surveillance system or classified by a case definition which are true cases. Also known as 'predictive value positive.'

PPS: See 'Probability proportional to size sampling.'

Precision: Refers to how well the results can be reproduced each time the survey is conducted.

Presumptive clinical diagnosis: Diagnosis made solely on the basis of symptoms, without the use of specific diagnostic tests.

Pre-surveillance assessment: Describes a set of activities that occur prior to beginning formal HIV and behavioural surveillance in *high-risk* groups. These activities include developing detailed plans and reviewing and collecting information that will help in planning and designing surveillance activities.

Prevalence: The proportion of persons in a given population with a disease or condition at a given point in time; a specific group infected. Prevalence is a direct measurement of the burden of disease in a population.

Prevalence assessment: Surveys that determine prevalence of a disease in a population.

Prevalence monitoring: Monitoring prevalence repeatedly over time to track trends.

Primary incentive: The incentive a participant gets for enrolling in the study and completing an interview.

Primary units: A sampling frame of larger unit. When it is difficult or impossible to make a list/sampling frame of each individual in the target population, we can develop a sampling frame of some larger unit; that is, clusters or primary sampling units. We then sample in stages by first sampling clusters and then sampling people within the clusters.

Priorities for Local AIDS Control Efforts (PLACE): A new, rapid assessment tool used to identify high transmission areas, which formalises the collection of information on high transmission areas. PLACE uses key informants to identify sites where people meet new sex partners, then interviews people at the site in order to characterise the site in each area and map sites, and, finally, interviews individuals socialising at the site to describe the characteristics of the people at the site.

Priority communicable disease: These are diseases that have the potential for epidemic spread and can be controlled through public health action. They are the diseases included in the Integrated Disease Surveillance form.

Prisoner: Any person involuntarily confined or detained in a penal institution, including persons detained pending arraignment, trial, or sentencing.

Probability proportional to size sampling: A class of unequal probability sampling in which the probability of a unit being sampled is proportional to the level of some known variable (Levy & Lemeshow).

Probability sampling: A sampling scheme that ensures that each entity in a population has a known, non-zero chance of being selected.

Process evaluation: An evaluation of a programme that determines how well the programme is functioning, as opposed to ‘impact evaluation.’

Proficiency panel: A set of samples designed to judge the accuracy and precision of a laboratory. A necessary component of laboratory quality assurance. In the context of HIV testing this may be a group that contains approximately six HIV-negative and HIV-positive (weak to strong) specimens representative of the HIV strains circulating in a country and of the different stages of HIV infection. The panel should be sent to participating laboratories once or twice each year for quality assurance testing.

Proficiency testing: The act of sending a proficiency panel to a laboratory, designed to test the accuracy and precision of that laboratory.

Prophylaxis: Treatment to prevent or suppress infection, often given before a person's exposure to the pathogen. For example, the treatment given to mother's during childbirth in order to prevent infection of the newborn child.

Proportion: The relationship of a part to the whole, in which the numerator is included in the denominator; often depicted as a percent by multiplying by 100.

Prospective case reporting: To watch a group of cases for outcomes, such as the development and progress of HIV disease, over time and to relate this to other factors such as suspected risk or protection factors.

Prostitués homosexuels: Homosexual prostitutes. Male sex workers who identify as homosexual or gay.

Protocol: The detailed plan for conducting a research study or other activities in which specific steps are required, including surveillance activities.

Purposive sampling: A non-random sampling method that involves choosing respondents with certain characteristics.

Qualitative research: Research that focuses on the characteristics or quality of things, rather than the quantity. The sample included qualitative research is usually much less used than that included in quantitative research.

Quality assurance: The dynamic and ongoing process of monitoring a system for reproducibility and reliability of results that permits corrective action when established criteria are not met.

Quality control: A laboratory's internal processes for running specimens to ensure that the test equipment and reagents function properly.

Quantitative research: Research that focuses on quantity of things, rather than the quality. Quantitative research has powerful tools for the analysis of numbers, but researchers know that the things counted are often qualitative categories or definitions.

Questionnaire faults: Problems with the way questions are phrased, set out and ordered, which lead to misunderstandings of the questions.

Random error: Also called non-systematic error. This is the type of error that results from chance and leads to imprecise results.

Random sample: A sample derived by selecting individuals such that each individual has the same probability of selection.

Random walk: A variation of link-tracing sampling procedure in which the respondent is asked to give the names of other members of a hidden population. From that list, one is selected randomly, located and added to the sample. The process is repeated for a desired number of waves. (S.K. Thompson et al.)

Range: The difference between the largest and smallest values in a distribution.

Rapid assessment and response (RAR): A method that is used to assess the nature and extent of a public health problem and to suggest ways to address the problem. RAR is not designed as a surveillance tool, but as a way to assess a situation quickly, and bring in resources to address it.

Rapid HIV test: An HIV antibody test that is simple, does not require any reagents or equipment other than what is contained in the kit and provides results in less than 20 minutes.

Rapid plasma reagin test (RPR): A common serologic test for syphilis. Specifically, a non-treponemal test for anticardiolipin antibodies.

Rate: An expression of the frequency with which an event occurs in a defined population.

Ratio: The quantitative relationship between two or more things; the value obtained by dividing one quantity by another.

RDS: See 'Respondent driven sampling.'

RDSAT: Acronym for respondent driven sampling analysis tool (a freeware software package for analysing RDS data).

Reference laboratory: A laboratory that functions as a recognised centre of expertise and standardisation of diagnostic techniques.

Referral coupon: Used by the recruiter to recruit a peer into the study.

Refugees: By legal definition, refugees are persons who are outside their country of nationality and who are unable or unwilling to return to that country. They cannot return due to a well-founded fear of persecution because of race, religion, political opinion or membership in an ethnic or social group.

Relative risk: A comparison of the risk of some health-related event such as disease or death in two groups. For example, an HIV-uninfected individual who has sexual intercourse with an HIV-infected person once a year may have a 5% chance of infection.

But if the uninfected individual uses a condom every time, the relative risk when compared to condom non-use is 15%.

Reliability: Refers to how reproducible a result is from repeated applications of a measure to the same subject.

Representative sample: A sample whose characteristics correspond to those of the original population or reference population.

Representativeness: The degree to which the sample truly reflects the study population (that is, whether it is representative of the study population).

Resistance: The ability of an organism, such as HIV, to overcome the inhibitory effect of a drug.

Resource assessment: A component of RAR, a systematic examination of the response (funds, people, buildings, knowledge) that is either available or required to solve the problem.

Respondent driven sampling (RDS): A sampling technique that does not require a sampling frame. It is an adaptation of a non-probability sampling method (snowball sampling) and is based on the assumption that members of the sub-population themselves can most efficiently identify and encourage the participation in surveillance of other sub-group members. RDS starts with initial contacts or 'seeds' who are surveyed and then become recruiters. Each of these recruiters is given coupons to use to invite up to three eligible people that he/she knows in the high-risk group to be interviewed. The new recruits bring their coupon to a central place where they are interviewed. The recruits then become recruiters. This occurs for five to six waves. Both the recruits and the recruiters are given incentives to encourage participation.

Retrospective case reporting: To look backwards and examine exposures to disease, for example, HIV infection, and suspected risk or protection factors in relation to an outcome (infection) that is established at the start of the reporting.

Retrovirus: A type of RNA virus that produces reverse transcriptase which converts RNA into DNA. HIV is an example of a retrovirus.

Reverse-transcription: The process by which HIV's genetic material (RNA) is transformed into DNA, which allows it to fuse with the host's genetic material (DNA).

RIBA: Acronym for recombinant immunoblot assay, also known as Western blot. Immunoblot assays confirm anti-HCV reactivity. Serum is incubated on nitrocellulose strips on which four recombinant viral proteins are blotted. Color changes indicate that antibodies are adhering to the proteins. A positive result is if two or more proteins react and form bands. An indeterminate result is if only one positive band is detected.

Risk: The probability that an event will occur; for example, that an individual will become ill within a stated period of time.

Risk factor: An aspect of personal behaviour or lifestyle; an environmental exposure; an inborn, inherited, or demographic characteristic. Associated with an increased occurrence of disease or other health-related event or condition. For example, injection drug use is a risk factor for acquiring HIV.

RPR: See 'Rapid Plasma Reagin test.'

Safety protocol: A study document that describes how to deal with field incidents or adverse events.

Sample: A selected subset of a population. There are specific types of samples used in surveillance and epidemiology such as convenience, systematic, population-based and random.

Sample size: The number of subjects to be used in a given study.

Sample frame: A list of units from which a sample may be selected. A sample frame is a fundamental part of probability sampling.

Sampling bias: Also called selection bias. This refers to errors in sampling that decrease accuracy and lead to incorrect estimates. We also use the term 'biased samples' to mean that errors were made in choosing the people in the sample.

Sampling element: Individual member of the population whose characteristics are to be measured. See 'Sampling unit.'

Sampling error: The part of the total estimation error of a parameter caused by the random nature of sampling.

Sampling interval: The standard distance between elements selected in the sample population.

Sampling scheme: Procedure for choosing individuals to be included in a sample.

Sampling units: Refers to individual members of the population whose characteristics are to be measured. See 'Sampling element.'

Sampling variation: Difference between the estimate you measure in a sample and the true value of the variable in the study population.

Scale line graph: A graph that represents frequency distributions over time where the Y-axis represents frequency and the X-axis represents time

Second-generation surveillance*:* Built upon a country's existing data collection system, second-generation HIV surveillance systems are designed to be adapted and modified to meet the specific needs of differing epidemics. This form of surveillance aims to improve the quality and diversity of information sources by developing and implementing standard and rigorous study protocols, using appropriate methods and tools. Second generation surveillance refers to activities outside of those activities generally considered to be a part of routine case surveillance such as case reporting and sentinel sero-surveys and uses additional sources of data to gain additional understanding of the epidemic. It includes biological surveillance of HIV and other STIs, as well as systematic surveillance of the behaviours that spreads them.

Secondary incentive: The incentive a participant gets for recruiting his or her peers into the study.

Seeds: Non-randomly selected (by the investigators) members of the target population who will initiate the RDS recruitment process by recruiting members of his or her peer group. From each seed, a recruitment chain is expected to grow.

Selection bias: A systematic error in the process respondent selection for a study or survey.

Sensitivity: The proportion of persons with disease who are correctly identified by a screening test or case definition as having disease.

Sentinel case reporting: Reporting cases of a disease from sentinel sites.

Sentinel populations: Populations that are subject to sentinel surveillance activities. They may not necessarily be representative of the general population, but rather they might be the first affected by HIV. Examples include sexually transmitted infection patients or truck drivers.

Sentinel sites: Sites at which sentinel surveillance activities take place, including clinics attended by individuals who may or may not be representative of the general population but are likely to represent groups initially infected or at higher risk for infection than the general population.

Sentinel surveillance: A surveillance system in which a pre-arranged sample of reporting sources at ‘watch post’ or ‘sentinel’ sites agrees to report all cases of one or more notifiable conditions. Often designed to provide an early indication of changes in the level of disease. Depending on the nature of the population surveyed, these data may be representative of the general population, or they may simply give more detailed information about the populations tested.

Sero-conversion: The development of antibodies to a particular microbe. When people develop antibodies to HIV, they ‘sero-convert’ from HIV-negative to HIV-positive.

Sero-incidence surveillance: Collecting blood samples for measuring newly acquired HIV infection for the purposes of surveillance.

Serologic test: A blood test that determines the presence of antibodies to particles such as viruses. For example, a blood test that detects the presence of antibodies to HIV.

Sero-prevalence: The proportion of a population that is infected, as determined by testing blood for the appropriate antibody. For example, the proportion of a population that is infected with HIV, as determined by testing for HIV antibodies in blood samples.

Sero-prevalence surveillance: Collecting blood samples for the purpose of surveillance. Latent, sub-clinical infections and carrier states can thus be detected, in addition to clinically overt cases. This is especially important in the case of HIV and other STIs, which often have a long latent period before symptoms are apparent.

Sero-status: Refers to the presence/absence of antibodies in the blood. For example, the presence or absence of HIV.

Sero-surveillance: Collecting blood samples for the purpose of surveillance. Latent, sub-clinical infections and carrier states can thus be detected, in addition to clinically overt cases. This is especially important in the case of HIV and other STIs, which often have a long latent period before symptoms are apparent.

Sexual transmission: Transmission of an infectious agent, such as HIV, that occurs predominately through unprotected vaginal or anal intercourse, and less frequently through oral intercourse.

Sexually transmitted diseases: Symptomatic. Caused by organisms that are spread by sexual contact from person to person.

Sexually transmitted infection (STI): Asymptomatic. Diseases that are spread by the transfer of organisms from person to person during sexual contact.

Sex workers (SWs): Persons who engage in **sex work**, or the exchange of sex for money, which includes many practises and occurs in a variety of settings. These may include '**direct**' or '**formal**' sex workers, who are sometimes included in registries and often found in brothels, and '**indirect**' or '**casual**' sex workers, who do not engage in sex work full time and are unlikely to be included in registries. The term 'sex worker' can be used to refer to female, male and transgendered sex workers.

Simple random sampling (SRS): Sampling where everyone has an equal chance of being randomly selected (a non-zero probability) and we know what that chance is.

Skewed: A distribution that is asymmetrical and does not follow a normal (bell-shaped) distribution.

Snowball sampling: Relies on informants to identify other relevant study participants in a chain referral pattern. Informants (seeds) who meet inclusion criteria are identified. This sampling design is based on chain referral and relies on the seed(s) to identify other relevant subjects for study inclusion. Those other subjects may identify other relevant subjects for inclusion. Snowball sampling is useful for studying populations that are difficult to identify or access. Representativeness is limited.

Social influence: Mild peer pressure from the recruiter who will receive a secondary incentive for recruiting his/her peers.

Social network: Members of a peer group who know each other.

Socio-metric stars: Seeds who are not only willing to recruit their peers, but are well-regarded by their peers and have a lot of them. Such seeds are more likely to influence others to be recruited into the study.

Specificity: The proportion of persons without disease who are correctly identified by a screening test or case definition as not having disease.

SRS: See simple random sampling.

Stacked bar chart: See 'clustered bar chart.'

Stakeholders (or stakeholder's group): Those with an interest in the results of surveillance activities. Includes public health practitioners, healthcare providers, data providers and users, representatives of affected communities; governments at the district, province and national levels; members of professional and private non-profit and donor organisations.

Standard error: Estimate of precision in probability sampling that can be used to construct a range of values within which the true population measure is likely to fall. We usually want to be 95% sure that the true population measure lies in our range.

Standardised Testing Algorithm for Recent HIV Sero-conversion (STARHS): A calculation for measuring new infection that uses a single blood test. STARHS uses the results of two EIA tests, one highly sensitive and another modified to be less sensitive. The less sensitive EIA test is called the 'detuned' assay.

Statistics: A branch of applied mathematics concerned with the collection and interpretation of quantitative data and the use of probability theory to estimate population parameters.

Steering method: In RDS, using additional methods to recruit a special sub-population of interest; for example, providing an extra coupon to be used only to recruit female IDUs.

STI: See ‘sexually transmitted infection.’

Stigma: A mark of disgrace or shame. For example, in some societies, being infected with HIV causes a person to be stigmatised.

Strata: A sub-group in stratified sampling.

Strategic information (SI): Refers to any data collected by surveillance or monitoring and evaluation of a programme or system. Includes, but is not limited to, process indicators, output indicators and surveillance data.

Stratification: The classification of a survey population into sub-groups or strata on the basis of selected characteristics.

Stratified and constant incentives: In a study of SWs, a constant incentive level was considered too low to attract the more hidden SWs who earned a higher income. The research team considered using a stratified incentive process. The SWs received an incentive based on the type of sex work they did. For instance, a street-based SW received a $5.00 incentive, while a call-girl-type SW received a $10.00 incentive

Stratified sampling: Stratified sampling is generally used to obtain a representative sample when the population is heterogeneous, or dissimilar, where certain homogeneous, or similar, sub-populations can be isolated (strata). A stratified sample is obtained by taking samples from each stratum or sub-group of a population.

Street children: Children who live and/or work on the streets, including orphaned, homeless, runaway, or neglected children who live chiefly in the streets without adequate protection, supervision, or direction from responsible adults.

Subcutaneously: Below the skin, as in an injection.

Sub-population: See ‘population sub-group.’

Sufficient cause: A causal factor or collection of factors whose presence is always followed by the occurrence of the effect (of disease).

Surveillance: The systematic collection, analysis, interpretation, and dissemination of health data on an ongoing basis, to gain knowledge of the pattern of disease occurrence and potential in a community, in order to control and prevent disease in the community.

Surveillance sites: The places from which case reports are obtained. This includes sites at which universal reporting and sentinel reporting are done. These may be healthcare facilities or other locations at which sero-surveys are conducted.

Survey population: The target population modified to take into account practical considerations (for example, all commercial sex workers in a city over the age of 15, excluding those who are based at home, as they cannot be accessed).

Survey protocol: A manual that describes all the steps and tasks involved in a sero-survey.

Survival sex: To barter sex for the necessities of living, such as food, shelter, goods, money. Engaged in by vulnerable populations, for example, by displaced women, street children, and transgendered people who are marginalised and discriminated against.

Susceptible: Vulnerable or predisposed to a disease.

Symptomatic: Exhibiting symptoms.

Symptoms: Any perceptible, subjective change in the body or its functions that indicates disease or phases of disease, as reported by the patient.

Syndrome: A group of symptoms as reported by the patient and signs as detected in an examination that together are characteristic of a specific condition.

Syndromic case reporting: A surveillance system in which a diagnosis of the infection is made through the presence of symptoms using a standard case definition. Frequently used for surveillance of sexually transmitted infections in countries in which access to laboratory testing may be limited.

Syndromic prevalence: The prevalence of a particular syndrome, or set of symptoms, in a given population. Usually calculated when testing equipment is not available to verify the presence of particular pathogen in a laboratory.

Syphilis: A sexually transmitted disease resulting from infection with the bacterium *Treponema pallidum*. Syphilis can also be acquired by newborns from their mothers during pregnancy.

Systematic sampling: A sampling method that consists of randomly selecting the initial patient who meets the inclusion criteria and then selecting every ‘nth’ (for example, third or fifth) eligible patient thereafter until the predetermined sample size is reached or the survey period is over.

Systemic: Concerning or affecting the body as a whole.

Table: A set of data arranged in rows and columns.

Target population: The group that meets a survey’s measurement objective (for example, all commercial sex workers in a city).

Targeted sampling: Targeted sampling uses pre-existing indicator data (qualitative and quantitative) to construct a sampling frame from which recruitment sites are then randomly selected. Qualitative indicator data includes ethnographic data and key informant interviews. Types of quantitative indicator data include cases of HIV/AIDS and STIs, admissions to drug treatment and population characteristics from census data. There are several limitations: 1) indicator data may not be useful in characterising the target population; 2) sampling may be biased and difficult to replicate; 3) geographic areas may not be sampled in proportion to the number of members in the population of interest; 4) the population of interest may not be sampled in proportion to the intensity of risk behaviour and 5) the probability of selecting a member of the population of interest may not be known.

TB: Acronym for tuberculosis.

Testing (HIV) strategy: The use of an appropriate HIV test or combination of HIV tests. The choice of testing strategy used is based on the objective of the test, the sensitivity and specificity of the test, and HIV prevalence in the population being tested.

T-helper lymphocyte: Also known as 'T-cell.' Immune cells that seek and attack invading organisms. HIV enters T-cells through their CD4 receptor proteins, making T-cells virtual HIV-factories.

Time-location sampling (TLS): Similar to conventional cluster sampling, but gets around the problem of clusters that are not stable (that is, clusters where the number and type of people vary by, for example, time of day). Time-location sampling allows the same site to be included in the sample frame more than once (for example, at different times of the day or different days of the week).

Timeliness of reporting: One of several attributes of a surveillance system. Timeliness may be defined as the time period between the diagnosis of the disease and the receipt of a case report form at the health district.

Transactional sex: Distinct from other forms of commercial sex. Includes the receipt of gifts or services in exchange for sex.

Transgendered persons: Persons who identify with or express a gender and/or sex different from their biologic sex.

Transition probability: The likelihood that a person will change from one state to another, for example becoming HIV positive.

Transmission: Any mode or mechanism by which an infectious agent is spread through the environment or to another person.

Trend: A long-term movement or change in frequency, usually upwards or downwards.

Treponema pallidum: The bacterial causative agent of syphilis.

Triangulation: The process of examining several different sets of data, which are measuring different things to come up with a better understanding of how and where an epidemic is spreading. For example, the use of antenatal clinic data, census data, and registered deaths in order to create a more complete picture of the AIDS burden in a country.

***Trichomonas vaginalis*:** A sexually transmitted protozoan parasite that causes the vaginal infection, **trichomoniasis**, characterised by itching, burning and vaginal discharge. Reinfection is common if sexual partners are not treated simultaneously.

True negatives: Test results that are negative when the patient actually does not have the disease that is being tested for.

True positives: Test results that are positive when the patient actually has the disease that is being tested for.

Tuberculosis: An airborne, often fatal bacterial infection caused by *Mycobacterium tuberculosis.* It causes damage to the lungs and other parts of the body. Infection is more likely in people with weak immune systems.

UAT: See 'unlinked anonymous testing.'

UNAIDS: Acronym for The Joint United Nations Programme on HIV/AIDS.

UNGASS: Acronym for United Nations General Assembly Special Session on HIV/AIDS.

Univariate analysis: The most basic, yet often the most important, type of behavioural surveillance analysis, because it shows the distribution of each variable. Most of the indicators defined for behavioural surveillance purposes are calculated through univariate analysis. They would include variables like the proportion of young men who have had sex with more than one partner during a given time period. When trends are analysed, statistical techniques are used to calculate how likely it is that changes in the proportions could have occurred by chance, or whether observed changes are likely to reflect real changes.

Universal case reporting: A surveillance system in which all persons who are identified as meeting the case definition for a particular disease are reported. For example, all persons with AIDS who receive care at any healthcare facility are reported. This is in contrast to sentinel reporting in which only selected sentinel sites report all persons who meet the case definition.

Universal conscription: Military conscription in which all physically able men between certain ages (for example 17-28) must perform military service.

Universal precautions: Recommendations issued by CDC to minimise the risk of transmission of bloodborne pathogens, particularly HIV and HBV, by healthcare and public safety workers. Barrier precautions are to be used to prevent exposure to blood and certain body fluids of all patients.

Unlinked anonymous testing (UAT): Testing that occurs when a sample of blood originally collected for other purposes is tested for HIV after being anonymised. The person whose blood is taken does not know that his/her blood will be tested for HIV. All information that could identify the person is removed from the sample so that the results of the test cannot be linked back to them.

Unprotected sex: Having sex without using a condom as protection against HIV and other sexually transmitted infections.

Urethritis: Inflammation of the urethra.

Vaccine: When injected into an individual, a vaccine protects against subsequent infection by a particular organism or results in a less severe illness should infection occur. Currently there is no vaccine for HIV.

Validity: The validity of a measure is the extent to which it actually measures what it is suppose to measure: the truth.

Values: Magnitude of measurements (statistics).

Variable: Any characteristic or attribute that can be measured.

VCT: See 'voluntary counselling and testing.'

VDRL: See 'Venereal Disease Research Laboratory test.'

Venue-based: Locations in the community, such as bars, tea houses, and street corners.

Venue-based sampling: Recruit respondents in places and at times where they would reasonably be expected to gather. The venues act as screeners in identifying potential respondents. Venue-based sampling requires comprehensive formative research.

Venereal Disease Research Laboratory test (VDRL): A common serologic test for syphilis. Specifically, a non-treponemal test for anticardiolipin antibodies.

Vertical surveillance system: See 'categorical surveillance system.'

Vertical transmission: See 'perinatal transmission.'

Vesicular: Pertaining to vesicles or blisters.

Viral load: The amount of HIV in the circulating blood. Also known as 'viral burden' or 'viral dose.'

Viral load test: Test that measures the quantity of HIV in the blood.

Virulence: The relative capacity of an organism to overcome the body's immune defences.

Virus: Micro-organisms that typically contain a protein coat surrounding nucleic acid (RNA or DNA) that are capable of growth only within living cells.

Vital records: Certificates of birth, death, marriage and divorce that are required by law.

Voluntary counselling and testing (VCT): A programme that provides both counselling and testing services to communities, allowing persons who are tested to obtain emotional and medical support before and after their HIV tests.

Voluntary migrants: People who temporarily work or travel away from their homes.

Volunteerism: A term used to describe overly cooperative subjects, leading to a potential bias if such cooperative people differ from the rest of the population of interest.

Vulnerable population: A group whose members are discriminated against and who face stigma, making them vulnerable to negative consequences of surveillance, including social and physical harm.

Western blot: A type of HIV test, Western blot uses an electroblotting method in which proteins are transferred from a gel to a thin, rigid support and detected by binding of labeled antibody to HIV.

WHO: Acronym for the 'World Health Organization.'

Width: See 'interval width.'

X-axis: The horizontal line of a graph, usually found at the bottom.

Y-axis: The vertical line of a graph, usually found at the left but sometimes also at the right.

Years of potential life lost: A measure of the impact of premature mortality on a population, calculated as the sum of the differences between some predetermined minimum or desired life span and the age of death for individuals who died earlier than that predetermined age.

YLL: See 'years of potential life lost.'

Appendix C, Useful Links

Organisational Sites

The Body
An AIDS and HIV Information Resource based in New York City, NY, USA. Provides Information on various questions related to HIV/AIDS
www.thebody.com

The CDC Global AIDS Program (GAP)
The CDC Global AIDS Program (GAP) Surveillance team are developing an interactive sampling selection tool for use in surveillance study sampling design. Proper sampling design is critical to the success of your study. The tool is scheduled to become available in 2007. The date of release and the URL will be announced by various means, through CDC-GAP and WHO regional offices.

Cochrane HIV/AIDS Group
An affiliate of the International AIDS Society and the UCSF AIDS Research Institute, the Cochrane Collaborative Review Group on HIV Infection and AIDS is an international network of health-care professionals, researchers and consumers working to prepare, maintain and disseminate systematic reviews on the prevention and treatment of HIV infection and AIDS.
www.igh.org/Cochrane

Council for International Organizations of Medical Sciences (CIOMS)
Council for International Organizations of Medical Sciences (CIOMS) has prepared the "International Ethical Guidelines for Biomedical Research Involving Human Subjects", in collaboration with the World Health Organization. This document can be accessed at:
http://www.cioms.ch/frame_guidelines_nov_2002.htm

Family Health International (FHI)
Family Health International has pioneered ways to curtail the spread of HIV/AIDS. Many of the HIV prevention "best practices" in use today have emerged from FHI's work in more than 60 countries.
www.fhi.org/en/HIVAIDS

The Global Fund to Fight AIDS, Tuberculosis and Malaria
The Global Fund was created to finance a dramatic turnaround in the fight against AIDS, tuberculosis, and malaria. These three diseases kill more than six million people a year. This massive scaling-up of resources is already supporting aggressive interventions against all three.
www.theglobalfund.org

HIV InSite
HIV InSite is developed by the Center for HIV Information (CHI) at the University of California, San Francisco (UCSF). HIV InSite's mission is to be a source for comprehensive, in-depth HIV/AIDS information and knowledge.
hivinsite.ucsf.edu

HIV/AIDS Rapid Assessment Guide
Family Health International (FHI) has prepared a HIV/AIDS rapid assessment guideline. A copy of this guideline can be found at:
http://www.fhi.org/en/HIVAIDS/pub/guide/RapidAssessmentGuide/index.htm

HIV/AIDS Survey Indicators Database
The HIV/AIDS Survey Indicators Database is overseen by a technical advisory committee that includes representatives from USAID, UNICEF, CDC, UNAIDS, WHO, US Census Bureau, Family Health International, MEASURE Evaluation, The Synergy Project, and MEASURE DHS+ (the implementing organisation). USAID is currently the primary funder for the initiative, with UNAIDS and UNICEF providing additional support. There are 180 surveys available in the database.
www.measuredhs.com

International Organization for Migration (IOM)
The International Organization for Migration (IOM) is the leading inter-governmental organization in the field of migration and works closely with governmental, intergovernmental and non-governmental partners. The IOM has extensive information on various migrant populations.
www.iom.int/

Multiple Indicator Cluster Survey (MICS), UNICEF
The Multiple Indicator Cluster Survey (MICS) is a household survey programme developed by UNICEF to assist countries in filling data gaps for monitoring the situation of children and women. It is capable of producing statistically sound, internationally comparable estimates of these indicators.
www.childinfo.org

Respondent-Driven Sampling (Cornell)
Defines RDS and provides information on minimum data requirements, sampling references, intervention references and downloads.
http://www.respondentdrivensampling.org

UNAIDS (Joint United Nations Programme on HIV/AIDS)
As the main advocate for global action on HIV/AIDS, UNAIDS leads, strengthens and supports an expanded response aimed at preventing the transmission of HIV, providing care and support, reducing the vulnerability of individuals and communities to HIV/AIDS and alleviating the impact of the epidemic.
www.unaids.org

UNAIDS epidemiological information on HIV/AIDS
www.unaids.org/en/resources/epidemiology.asp

UNAIDS surveillance information on HIV/AIDS
www.unaids.org/en/in+focus/topic+areas/surveillance+and+reporting.asp

United Nations Children's Fund (UNICEF)
UNICEF is one of the United Nations' key agencies in the fight against HIV/AIDS, mobilising financial resources and helping persuade governments to put HIV/AIDS at the top of their agendas and to treat the epidemic as a national emergency. UNICEF is working in 160 countries around the world to combat the epidemic.
www.unicef.org/aids

United Nations General Assembly Special Session (UNGASS)
This site is dedicated to tracking compliance with the United Nations General Assembly Special Session on HIV/AIDS (UNGASS), which in 2001 concluded with a declaration of commitment signed by 189 member states to take actions to reduce the spread and impact of HIV/AIDS. As part of this effort, UNAIDS reports on progress toward achieving this goal every two years. To measure progress, UNAIDS developed a set of 25 indicators called the UNGASS indicators.
http://www.ua2010.org/index.php/en/UNGASS

United Nations Office on Drugs and Crime (UNODC)
The United Nations Office on Drugs and Crime (UNODC) is a global leader in the fight against illicit drugs and international crime. UNODC is involved in HIV/AIDS programming in regions, such as the Eastern Mediterranean and North Africa, where injecting drug use is known to drive the HIV/AIDS epidemic.
http://www.unodc.org

United States Department of Commerce, U.S. Census Bureau's International Programs Center
The International Programs Center, part of the Population Division of the U.S. Bureau of the Census, conducts demographic and socio-economic studies and strengthens statistical development around the world through technical assistance, training, and software products. The IPS maintains an HIV/AIDS Surveillance database, the Monitoring the AIDS Pandemic (MAP) Network, and a series of HIV/AIDS country profiles. The Programs Center provides various country profiles that examine the patterns and trends of the epidemic, as well as maps and tables that serve to summarise the statistics for each region in a streamlined format.
www.census.gov/ipc/www/hivaidsn.html

World Bank, The Global HIV/AIDS Program
The Global HIV/AIDS Program was created in 2002 to support the World Bank's efforts to address the HIV/AIDS pandemic from a cross-sectoral perspective. The programme offers global learning and knowledge sharing on best practices to addressing HIV/AIDS.
www1.worldbank.org/hiv_aids/globalprogram.asp

World Health Organization (WHO)
The World Health Organization is the United Nations specialised agency for health. WHO's objective, as set out in its constitution, is the attainment by all peoples of the highest possible level of health. WHO is governed by 192 Member States through the World Health Assembly, composed of representatives from WHO's Member States.
www.who.int

WHO: Department of HIV/AIDS
The HIV/AIDS Department coordinates a strategic, organisation-wide response to the HIV/AIDS epidemic and enables WHO to provide enhanced technical support in HIV/AIDS to countries and regional offices.
www.who.int/hiv/en

WHO: Test Kit Evaluations
The WHO test kit evaluation programme aims to provide Member States, UN agencies, and other partners with technical information and advice on the quality of currently available test kits and technologies. Additional information is available at:
http://who.int/diagnostics_laboratory/evaluations/en/

US Centers for Disease Control and Prevention (CDC) and National Institutes of Health (NIH) Sites

Centers for Disease Control and Prevention (CDC)
CDC serves as the national focus for developing and applying disease prevention and control, environmental health, and health promotion and education activities designed to improve the health of the people of the United States.
www.cdc.gov

Global AIDS Program (CDC)
The Global AIDS Program (GAP) exists to help prevent HIV infection, improve care and support and build capacity to address the global HIV/AIDS pandemic.
www.cdc.gov/nchstp/od/gap

Division of HIV/AIDS Prevention (CDC)
The mission of the Division of HIV/AIDS Prevention is to prevent HIV infection and reduce the incidence of HIV-related illness and death, in collaboration with community, state, national and international partners.
www.cdc.gov/hiv/dhap.htm

Division of AIDS, STD, and TB Laboratory Research (CDC)
The Division of AIDS, STD, and TB Laboratory Research (DASTLR) was established to centralise CDC's laboratory studies on human immunodeficiency virus (HIV), other retroviruses, other sexually transmitted diseases (STDs), hematologic disorders, and mycobacteria, including *Mycobacterium tuberculosis*.
www.cdc.gov/ncidod/dastlr

National Center for HIV, STD, and TB Prevention (CDC)
Umbrella organisation at the CDC for the divisions listed above.
www.cdc.gov/nchstp/od/nchstp.html

National Institutes of Health (NIH)
National Institutes of Health is the Federal focal point for medical research in the United States. The NIH, comprising 27 separate institutes and centres, is one of eight health agencies of the Public Health Service, which, in turn, is part of the U.S. Department of Health and Human Services. Simply described, the goal of NIH research is to acquire new knowledge to help prevent, detect, diagnose and treat disease and disability.
www.nih.gov

National Library of Medicine (NLM)
NLM provides a wide variety of resources related to the biomedical and health sciences. The Web site has information on how to access the various NLM databases, including how to establish an account for free access to its HIV/AIDS databases.
www.nlm.nih.gov

National Institute of Allergy and Infectious Diseases (NIAID)
News releases from the NIH's primary AIDS research institute, plus AIDS reagent programme catalogue and other information.
www.niaid.nih.gov

National Institute on Drug Abuse (NIDA)
NIDA's mission is to lead the nation in bringing the power of science to bear on drug abuse and addiction. This charge has two critical components: The first is the strategic support and conduct of research across a broad range of disciplines. The second is ensuring the rapid and effective dissemination and use of the results of that research to significantly improve drug abuse and addiction prevention, treatment, and policy.
www.nida.nih.gov

Division of AIDS and Health and Behavior Research of the National Institute of Mental Health
The Division of AIDS and Health and Behavior Research (DAHBR) supports research and research training to: develop and disseminate behavioural interventions that prevent HIV/AIDS transmission, clarify the pathophysiology and alleviate the neuropsychiatric consequences of HIV/AIDS infection and use a public health model to reduce the burden of mental illness
www.nimh.nih.gov/dahbr/dahbr.cfm

National Institute for Child Health & Human Development (NICHD)
NICHD is part of the National Institutes of Health, the biomedical research arm of the US Department of Health and Human Services. The mission of the NICHD is to ensure that every person is born healthy and wanted, that women suffer no harmful effects from the reproductive process, and that all children have the chance to fulfil their potential for a healthy and productive life, free of disease or disability.
www.nichd.nih.gov

Fogarty International Center
The Fogarty International Center promotes and supports scientific research and training internationally to reduce disparities in global health.
www.fic.nih.gov

NIH Office of AIDS Research (OAR)
NIH's OAR is located within the Office of the Director of NIH and is responsible for the scientific, budgetary, legislative and policy elements of the NIH AIDS research programme.
www.nih.gov/od/oar

Other U.S. Government Sites

United States Agency for International Development
USAID is an independent federal government agency that receives overall foreign policy guidance from the Secretary of State. The agency works to support long-term and equitable economic growth and to advance U.S. foreign policy objectives by supporting: economic growth, agricultural and trade, global health, democracy, conflict prevention and humanitarian assistance.
www.usaid.gov

Development Experience Clearinghouse
The Development Experience Clearinghouse (DEC) is the largest online resource for USAID-funded, international development documentation, including fact sheets on HIV/AIDS in the Eastern Mediterranean and North Africa.
www.dec.org

United States Department of Commerce, U.S. Census Bureau's International Programs Center
The International Programs Center, part of the Population Division of the U.S. Bureau of the Census, conducts demographic and socio-economic studies and strengthens statistical development around the world through technical assistance, training, and software products. The IPS maintains an HIV/AIDS Surveillance database, the Monitoring the AIDS Pandemic (MAP) Network, and a series of HIV/AIDS country profiles.
http://www.census.gov/ipc/www

Veterans Health Administration: Public Health Strategic Health Care Group, AIDS Information Center
Provides a variety of educational links related to HIV/AIDS care, treatment, policy and research. Detailed information is also provided on blood exposure and needle stick safety in healthcare settings as well as treatment guidelines and recommendations.
vhaaidsinfo.cio.med.va.gov/aidsinfo/TOC.htm

Appendix D, Answers to Warm-Up Questions

Answers are provided in italics for each unit's warm-up questions.

Answers to the small group discussion questions are not included. Small group discussion questions are designed to stimulate small group discussion among participants in the workshop or class, and answers will vary widely.

Unit 1 Answers

Warm-up questions

1. Which of the following groups are at high risk for HIV infection worldwide?

    a. sex workers
    b. injecting drug users
    c. men who have sex with men
    d. all of the above

    Worldwide, groups at high risk for HIV infection include, but are not limited to: sex workers, injecting drug users, men who have sex with men, mobile populations, street children, out-of-school youth, prisoners, and uniformed personnel.

2. True or false? In low-level epidemics, surveillance of most-at-risk populations can serve as an early indicator of the presence of HIV in a country.

    True. At the beginning of an epidemic, the first infections often appear in high-risk groups because they have higher-risk behaviours than the general populations.

3. List the two sampling methods that are commonly used in HIV surveillance of most-at-risk populations.

    Respondent-driven sampling and time-location sampling (RDS) and (TLS) are ideally suited for surveys of high-risk groups, especially those that are harder to find.

4. What are some potential consequences of not protecting participants' privacy and confidentiality?

Potential consequences include physical, psychological, legal, and social harms. If a person's HIV infection becomes known, he or she may suffer discrimination or stigma, or may even be subject to criminal charges in some situations.

Unit 2 Answers

Warm-up questions

1. True or false? SWs can contribute disproportionately to the sexual transmission of HIV because of their large number of sexual partners.

   True. Because their clients can infect others in the general population, sex workers contribute greatly to sexual HIV transmission.

2. Other than brothels, what are some of the locations where direct SWs (SWs who work exclusively in sex work and have no other occupation) can be found?

   Direct sex workers can be found in streets, hotels, and bars, and may work exclusively in sex work.

3. What term is used to describe sex workers who do not engage in sex work full time and may have another source of income? (They are also called casual SWs or clandestine SWs.)

   Indirect sex workers. Indirect sex workers sell sex to supplement their primary income, and are also known as 'casual' or 'clandestine' sex workers. Indirect sex workers often can be found in bars or massage parlours.

4. True or false? Surveillance co-ordinators should meet with SWs to use their expertise in designing the approach and questionnaires for behavioural surveillance.

   True. Sex workers often have inside information that could help you design a more effective approach to surveillance.

5. SWs and their clients are often a ***bridge*** to other high-risk populations. Clients of SWs, for example, may transmit HIV to their wives and non-commercial sex partners.

   The infected clients of sex workers can serve as a bridge for spreading infection to the general heterosexual population. A bridge population is a group that serves to encourage the spread of HIV from a high-risk group to the general population.

6. Name a sampling method that could be used among highly mobile sex workers, such as those who do not work in brothels.

   Respondent-driven sampling can be used to sample highly mobile sex workers.

Unit 3 Answers

Warm-up questions

1. List two examples of blood-to-blood (or parenteral) transmission of HIV.

   Examples include transfusions, needle stick injuries, needle re-use in medical settings, and injection of illegal drugs.

2. Which of the following sampling methods can be used for surveillance among IDUs?

   a. time-location sampling
   b. multi-stage cluster sampling
   c. convenience sampling
   d. simple random sampling from a drug treatment clinic registry

   Along with respondent-driven sampling, time-location sampling is an ideal method for surveying hard-to-reach populations.

3. List two organisations with which you can form alliances as you develop your HIV surveillance system for IDUs.

   Examples include treatment clinics, needle-exchange programmes, prisons, and social service organisations.

4. List two interventions that can help reduce HIV transmission among IDUs.

   Interventions that can help to reduce HIV transmission among IDUs include promoting sterilisation of injection equipment, providing sterile needles, treating drug addiction, and promoting condom use.

5. What are the ethical issues you must consider when conducting surveillance among IDUs?

   Ethical issues to consider when conducting surveillance in IDUs include:

   - *The inability of IDUs to provide true informed consent when under the influence of drugs or withdrawing from a drug.*
   - *Participation in surveillance activities may place IDUs at risk for harm and discrimination due to inadvertent identification as an IDU or as HIV-infected.*

Unit 4 Answers

Warm-up questions

1. True or false? Because men who have sex with men (MSM) are homosexual, there is little risk that HIV will spread to the rest of the population, including women.

   False. MSM often have sex with both men and women, meaning that they are likely to transmit any infections they have to their female and male partners.

2. List two possible points of access where MSM can be found.

   Although MSM are often hidden because of discrimination, in some countries there are well-defined gay communities that congregate at known locations. Examples of these include dance clubs, gyms, bath houses, and parks.

3. Given that MSM are often hard to reach because of discrimination and stigmatisation, two successful sampling methods in this group are _____ and _____.

   Time-location sampling and respondent-driven sampling.

4. What are some of the ethical issues to consider when conducting HIV surveillance of MSM?

   MSM are considered a vulnerable population. Their participation in surveillance activities may place them at risk for harm and discrimination, including: loss of confidentiality, inadvertent identification as an MSM, inadvertent disclosure of HIV status, negative reaction and backlash in response to publicised results, physical abuse and imprisonment.

5. What are some possible behavioural indicators to include when conducting HIV surveillance among MSM?

   Behavioural indicators to incorporate in surveys of MSM may include information on condom use, number of partners, type of partners, frequency of unprotected insertive anal intercourse (UAI), frequency of unprotected receptive anal intercourse (URAI), STI treatment-seeking, migration patterns, marital status, and history of sex work.

6. What are some possible biological measures to include when conducting HIV surveillance among MSM?

   Biological measures to incorporate in surveys of MSM may include syphilis, gonorrhoea, Chlamydia, herpes simplex virus type-2, and syndromic proctitis.

Unit 5 Answers

Warm-up questions

1. Which of the following terms is used to describe migrant labourers, fisherman, and truck drivers?

   a. involuntary migrants
   b. voluntary migrants
   c. military personnel
   d. none of the above

   Voluntary migrants are often young men and women who leave their rural communities to work in urban areas or construction sites. Voluntary migrants also include people in the transportation industry,

such as truck drivers and merchant seamen, who travel frequently across long distances.

2. Which of the following terms is used to describe refugees and internally displaced persons?

   a. involuntary migrants
   b. voluntary migrants
   c. military personnel
   d. none of the above

   Involuntary migrants include refugees and internally displaced persons. The term 'refugee' only applies to persons who have been displaced from their homelands and have sought refuge in a second country. Internally displaced persons are persons who have left their homes due to civil unrest, natural disasters, and political and/or religious persecution, but have not crossed an internationally recognised state border.

3. Of the following, which is *not* a reason why migrants are especially vulnerable to HIV?

   a. Female migrants may sell 'survival sex' when they have no other source of income.
   b. Migrants usually have only one sexual partner.
   c. Migrants have limited access to healthcare.
   d. Migrants often live in settings where they are more likely to adopt risk behaviours.

   As they are often away from home for extended periods of time, migrants often have multiple sexual partners.

4. Mobile persons often serve as a *bridge* between female sex workers and the general population. Additionally, due to migration patterns, mobile populations may bring HIV from high-prevalence areas to low-prevalence areas.

   The role of migration in the spread of HIV has been described primarily as a result of men becoming infected while they are away from home, often by contact with infected sex workers, and infecting their wives or regular partners when they return.

5. List two possible locations where mobile persons may be found in large numbers.

   Possible locations where mobile persons may be found in large numbers include truck stops and roadside hotels, neighbourhoods known as refugee areas, refugee settings, and health clinics that serve refugees or IDPs.

6. What are some of the ethical issues to consider when conducting HIV surveillance among refugees or internally displaced persons?

   One of the ethical concerns surrounding HIV surveillance among refugees or internally displaced persons is the backlash that may result when these groups are identified as having a high prevalence of HIV or risk behaviours. This is particularly important when a high prevalence of HIV is discovered in a refugee population in an otherwise low-prevalence country.

Unit 6 Answers

Warm-up questions

1. What are some of the reasons why street children may be considered vulnerable to HIV?

   Street children may be more vulnerable to HIV infection for any of the following reasons: they do not receive reproductive health education and other school-based services, they are not exposed to the structure that the school environment would otherwise provide, they face stigma and discrimination that may prevent them from adopting risk-reduction behaviours, they are more likely to experiment with drugs and alcohol, and they may be sexually exploited, trafficked, or involved in the sex industry.

2. List three possible places where you would expect to find large numbers of street children.

   Locations where street children spend most of their time will differ by sub-group, and will be dependent on the particular sub-group of interest. To locate street children, identify areas where young people tend to congregate. These include beaches, parks, movie theatres, and sports clubs. Depending on the focus of the surveillance, other sub-groups, such as sex workers, intravenous drug users, or factory workers, may be included. In these cases, also consider brothels/massage parlours, bars/discos, other places where people gather to use drugs, truck stops, and factories employing youth workers.

3. List two organisations with which you can form alliances as you develop your HIV surveillance system for street children.

   Possible organisations that can help you locate and access street children include governmental bodies such as the Ministry of Social Development and the Ministry of Youth and Sports, the United Nations Children's Fund (UNICEF), the United Nations Populations Fund (UNFPA), the Red Cross and Red Crescent societies, Save the Children, day centres for street children, the World Association of Girl Guides and Girl Scouts, the Boy Scouts, Youth Scouts, OXFAM International, local and international local sports clubs, and NGOs that work with street children.

Unit 7 Answers

Warm-up questions

1. Which of the following is a reason for high HIV prevalence among prisoners?

   a. the over-representation of injecting drug users among prisoners
   b. male-to-male sex during long periods of incarceration
   c. sexual relations between prison staff and prisoners
   d. high concentration of female sex workers in some prisons
   e. the sharing of needles for drug use in prison
   f. *all of the above*

   Depending on whether prisoners are male or female, these reasons will differ.

2. True or false? The most practical way to collect information on HIV prevalence in prisons is to use the mandatory screening programmes when prisoners are admitted.

   True. If this option is not available, you will need to develop other sampling methods.

3. What is the simplest form of sampling that can be used if you are surveying prisoners who are already incarcerated?

   a. cluster sampling
   b. systematic random sampling
   c. snowball sampling
   d. time-location sampling

   A systematic random sample is the easiest and most appropriate method for this situation, since prisoners are not mobile or a hidden population.

4. True or false? High HIV prevalence among prisoners is a result of HIV infection both before and after entering the criminal justice system.

   True. There are multiple factors contributing to the high prevalence of HIV in prisons. These include the high concentration of arrested IDUs and sex workers, consensual and non-consensual male-to-male sex, especially during long periods of incarceration, syringe sharing with multiple injectors, and tattooing with unsafe needles.

5. Cohort studies provide the most exact measurements of incidence, but they require the studied groups to be relatively stationary. Which of the following groups can be surveyed using cohort studies?

   a. street-based sex workers
   b. migrant workers
   c. prisoners
   d. refugees

   Because prisoners are a relatively stationary group, calculating the incidence of HIV in prisons may be possible. Cohort studies provide the most exact measurements of incidence, but they are only possible if correctional staff allow public health workers access to prisoners for HIV testing.

6. Because of their inability to give true voluntary *informed consent*, prisoners are a vulnerable population and need special ethical protection.

   Prisoners are under unique constraints because of their incarceration, which affects their ability to make a truly voluntary and un-coerced decision about whether to participate as research subjects. For this reason, it is important to take special precautions when obtaining informed consent from prisoners.

Unit 8 Answers

Warm-up questions

1. List three reasons why uniformed personnel are at increased risk of HIV infection.

   Possible reasons include the following: personnel are usually young and sexually active; they are often away from home; they are surrounded by opportunities for casual sex; they are governed by peer pressure; and they are likely to feel invincible and take more risks.

2. Access to uniformed personnel is usually restricted. Military officials, such as senior commanders and medical officers, are important gatekeepers who can provide access to uniformed personnel.

   Prior to beginning surveillance activities, the surveillance team will need to form alliances at the highest levels, with the Ministry of Health and the Ministry of Defence for armed services, or with the Ministries of Interior or Justice for police. It will also be helpful to enlist the

support of those operating the current medical care and public health intervention programmes that exist for these populations.

3. *Informed consent* is required when conducting prevalence studies and other activities involving the non-routine collection of data.

   All data-collection activities, other than mandatory or clinical testing, usually require informed consent.

4. List two methods that may be used for sampling uniformed personnel.

   When uniformed personnel are not routinely tested for HIV, systematic sampling, cluster sampling or stratified sampling may be appropriate.

Unit 9 Answers

Warm-up questions

1. Out-of-school youth may include which sub-populations?

   a. street children
   b. child labourers
   c. adolescent sex workers
   d. married adolescents
   e. *all of the above*

   Out-of-school youth may have completed school, may have dropped out of school, or may never have started school. The experiences of OSY vary greatly—they may work in factories, hawk goods in markets, work on farms, stay at home to do housework or child-rearing, engage in prostitution, live on the streets, or be unemployed.

2. True or false? By targeting youth through behaviour-change campaigns, several countries have successfully decreased national HIV prevalence levels.

   True. Several countries have successfully decreased national HIV prevalence rates by specifically targeting youth with behaviour-change interventions.

3. List three possible places where you would expect to find large numbers of out-of-school youth.
   Locations where OSY spend most of their time will differ by sub-group and will be dependent on the particular sub-group of interest. To locate OSY, identify areas where young people tend to congregate. These include beaches, parks, movie theatres, and sports clubs. Depending on the focus of the surveillance, other sub-groups, such as OSY sex workers, intravenous drug users, or factory workers may be included. In these cases, consider brothels/massage parlours, bars/discos, parks, beaches, other places where people gather to use drugs, truck stops, and factories employing youth workers.

4. What are two reasons why out-of-school youth may be considered a vulnerable population?

   Out-of-school youth may be more vulnerable to HIV infection for any of the following reasons: they do not receive reproductive health education and other school-based services, they are not exposed to the structure that the school environment would otherwise provide, they face stigma and discrimination that may prevent them from adopting risk-reduction behaviours, they are more likely to experiment with drugs and alcohol, and they may be sexually exploited, trafficked, or involved in the sex industry.

Appendix E: Laboratory Tests Available for Measuring Biological Outcomes among Most-At-Risk Populations

Table 1: **Characteristics of *Candida* detection assays**

	Microscopy *wet mount*	Culture *>10^3cfu/ml*	Antigen detection	DNA detection
Sensitivity[1]	35-45%	67%	61-81%	80%
Specificity[1]	99%	66%	97%	98%
Advantages	rapid, inexpensive	sensitive	rapid, also detects Trichomonas	rapid, objective, also detects Trichomonas and Gardnerella
Disadvant-ages	subjective	requires 24 hours	expensive	expensive, requires special equipment and test read immediately after completion
Level of use	exam room, on-site lab	on-site lab, intermediate lab	exam room, on-site lab	intermediate lab, referral lab
Training	moderate	moderate	minimal	moderate
Equipment	light microscope	incubator, light microscope	none	heat block, special processor
Ease of performance	easy	moderate	easy	easy to moderate, automated
Cost	US$ 1.00	US$ 2.00	US$ 12.00 (includes detection of Trichomonas)	US$ 12.00 (includes detection of Trichomonas and Gardnerella)

[1]Sensitivity and specificity are for clinical signs and symptoms of vulvovaginal candidiasis.

Table 2: Characteristics of *Trichomonas* detection assays

	Microscopy	Culture	Antigen detection	DNA detection	
				Hybridization assay	*PCR*
Sensitivity[1]	38-82%	98%	86%	88-91%	93%
Specificity[1]	100%	100%	99%	100%	96%
Advantages	rapid, inexpensive	sensitive, diagnosis in men	rapid	rapid, objective, also detects Gardnerella and Candida	very sensitive, allows patient self-sampling
Disadvantages	low sensitivity, must be performed immediately, subjective	takes 1-4 days	expensive	expensive, requires special equipment and test read immediately after completion	expensive, requires expertise
Level of use	exam room on-site lab	on-site lab, intermediate lab	exam room, on-site lab	intermediate, referral lab	referral lab
Training	moderate	moderate	moderate/minimal	moderate	extensive
Equipment	light microscope	incubator, light microscope	light or fluorescent microscope/none	heat block, special processor	thermal cycler, microwell plate reader
Ease of performance	easy	easy	moderate/ easy	easy to moderate, automated	complex, automated
Cost	US$ 1.00	US$ 3.00	US$ 6.00-12.00 (includes detection of Candida)	US$ 12.00 (includes detection of Candida and Gardnerella)	$11.00

[1] Sensitivity and specificity are for detection of *T. vaginalis* by combined wet prep and culture results.

***Table 3:* Characteristics of bacterial vaginosis detection assays**

	Microscopy and metabolic product detection			DNA detection
	3 of 4 criteria	*Gram stain*	*Proline aminopeptidase*	*Hybridization assay*
Sensitivity[1]	81%	89%	93%	94%
Specificity[1]	94%	93%	93%	81%
Advantages	rapid, inexpensive	reproducible, standardized, inexpensive	objective	objective, can also detect Candida and Trichomonas
Disadvantages	subjective, some criteria nonspecific	requires expertise	takes longer than wet mount or stain	expensive, requires special equipment, test read immediately after completion
Level of use	exam room, on-site lab	on-site lab	on-site lab, intermediate lab	intermediate lab, referral lab
Training	moderate	moderate	minimal	moderate
Equipment	light microscope	light microscope	centrifuge, incubator	heat block, special processor
Ease of performance	easy	easy	easy	easy to moderate, automated
Cost	US$ 1.00	US$ 0.50	US$ 1.00	US$ 12.00 (includes detection of Candida and Trichomonas)

[1] Sensitivity and specificity are for diagnosis of BV by presence of 3 of 4 criteria and/or positive Gram stain.

Table 4: Characteristics of *Chlamydia* detection assays

	Microscopy	Antigen detection		RNA detection	Amplification & detection	
	DFA	*EIA*	*Rapid*	*Chemoluminescent DNA probe*	*PCR*	*LCR*
Sensitivity[1]	74%-90%	71%-97%	52%-85%	75-%85%	90%	90%-97%
Specificity[1]	98%-99%	97%-99%	> 95%	98%-99%	99%-100%	99%-100%
Advantages	rapid, easy	can batch samples	rapid, easy	also detects N. gonorrhoeae, automated	can detect N. gonorrhoeae in same sample, allow noninvasive sampling	less affected by inhibitors
Disadvant-ages	labour intensive, subjective	requires confirmation	insensitive, requires confirmation	less sensitive than PCR, requires confirmation	false negatives	no test for sample inhibitors
Level of use	on-site lab, intermediate	intermediate, referral lab	exam room, on-site lab	intermediate, referral lab	intermediate, referral lab	intermediate, referral lab
Training	moderate to extensive	moderate	minimal	moderate	moderate to extensive	moderate
Equipment	fluorescent microscope	microwell plate reader	none	heat block, luminometer	thermal cycler, incubator, microwell plate reader	thermal cycler, LCx processor
Ease of performance	moderate	moderate	easy	moderate	moderate to difficult, automated	moderate, automated
Cost	US$ 6.00	US$ 6.00	US$ 13.00-16.00	US$ 8.00	US$ 11.00 (US$ 14.00 for N. gonorrhoeae detection also)	US$ 16.00

[1] Sensitivity and specificity are for detection of C. trachomatis by culture or by DNA amplification test.

***Table 5:* Characteristics of *N. gonorrhoeae* detection assays**

	Microscopy	Culture	DNA Detection	Amplification & Detection	
			Hybridization assay	*PCR*	*LCR*
Sensitivity[1]	90%-95%	81%-100%	86%-100%	89%-97%	95%-100%
Specificity[1]	98%-100%	100%	99%	94%-100%	98%-100%
Advantages	rapid, inexpensive	gold standard, isolates available for further testing	rapid, viable organisms not required	viable organisms not required, extremely sensitive, allow non invasive sampling can detect C. trachomatis in same sample	
Disadvantages	insensitive for females	stringent handling, requires up to 3 days	expensive	expensive, requires expertise no test for sample inhibitors	
Level of use	on-site lab	on-site lab, intermediate	intermediate, referral lab	intermediate, referral lab	intermediate, referral lab
Training	moderate	moderate	moderate	moderate to extensive	moderate
Equipment	light microscope	incubator, light microscope, candle jar	water bath, luminometer	microfuge, thermal cycler, incubator, microwell reader	heat block, thermal cycler, microfuge, Imx processor
Ease of performance	easy	moderate	moderate	moderate to difficult, automated	moderate, automated
Cost	US$ 0.50	US$ 1.00 (+1-3 to confirm positive isolates)	US$ 6.00	US$ 11.00 (US$ 14.00 for C. trachomatis detection also)	US$ 14.00

[1] Sensitivity and specificity are for detection of *N. gonorrhoeae* in urethral, endocervical and urine samples by culture except for microscopy, which is for detection in urethral samples from symptomatic men.

Table 6: Characteristics of syphilis detection assays

	Microscopy	Antibody Detection		Antigen Detection	DNA Detection
	dark-field	*nontreponemal RPR*	*treponemal MHA-TP*		*multiplex PCR*
Sensitivity[1]	74%-86%	72%-100%	69%-90%	81%	91%
Specificity[1]	97%-100%	93%-98%	98%-100%	89%	99%
Advantages	positive early, rapid, specific, inexpensive	inexpensive, rapid, easy, antibody titer to follow treatment	specific, confirms non treponemal tests	detects T. Pallidum before antibodies are positive	sensitive, specific, allows self-collected sample
Disadvantages	insensitive, no oral sample, requires live treponemes	false positives, less sensitive for early disease	more difficult, more expensive	time consuming, expensive	inhibitors of PCR reaction cause false-negative results, complex, expensive
Level of use	exam room, on-site lab	on-site lab, intermediate lab	intermediate lab, referral lab	intermediate lab, referral lab	referral lab
Training	extensive	minimal	moderate	moderate	extensive
Equipment	light microscope with dark-field condenser	centrifuge, rotator	centrifuge	spectrophotometer	microfuge, thermal cycler, incubator, microwell plate reader
Ease of performance	easy	easy	moderate	moderate	complex
Cost	US$ 0.40	US$ 0.50	US$ 1.40	US$ 3.00	US$ 14.00 (includes detection of H. ducreyi and HSV)

[1] Sensitivity and specificity are for detection of primary syphilis. The sensitivity of both nontreponemal and treponemal antibody detection increases for detection of secondary syphilis. The sensitivity of nontreponemal antibody detection decreases for detection of latent and tertiary syphilis. The tests for *T. pallidum* are only relevant when lesions are present in primary and secondary syphilis. But these tests can detect latent untreated infection which can be important for patient outcomes, such as in pregnancy.

***Table 7:* Characteristics of genital herpes detection assays**

	Culture	Antigen detection	DNA detection *multiplex PCR*
Sensitivity[1]	gold standard	70%-95%	more sensitive than culture
Specificity[1]	100%	90%-100%	98%-100%
Advantages	sensitive, specific	rapid, relatively inexpensive, more sensitive than culture for detection in late-stage lesions	very sensitive, specific, allows self-collected sample
Disadvantages	expensive, time-consuming, requires expertise	less sensitive	inhibitors of PCR cause false-negative results, complex, expensive
Level of use	referral lab	intermediate lab, referral lab	referral lab
Training	extensive	moderate	extensive
Equipment	CO_2 incubator, microscope, (centrifuge)	fluorescent microscope or light microscope or microwell plate reader	microfuge, thermal cylcer, incubator, microwell plate reader
Ease of performance	complex	moderate	complex
Cost	US$ 40.00	US$ 4.00-8.00	US$ 14.00 (includes detection of T. Pallidum and H. ducreyi)

[1] The sensitivity of culture varies depending on the type of medium used and can only be estimated since there is no gold standard on which to base the diagnosis of chancroid.

***Table 8:* Characteristics of chancroid detection assays**

	Culture	Antigen detection	DNA detection *PCR*
Sensitivity[1]	56%-90%[1]	not determined	77%-98%[2]
Specificity[1]	100%	not determined	98%-100%
Advantages	isolates available for further testing	faster	very sensitive
Disadvantages	insensitive, proper medium difficult to obtain	not commercially available	inhibitors of PCR cause false-negative results, complex, expensive
Level of use	on-site lab	referral lab	referral lab
Training	moderate	moderate	extensive
Equipment	incubator, light microscope, candle jar	fluorescent microscope or microwell plate reader	microfuge, thermal cycler, incubator, microwell plate reader
Ease of performance	difficult	moderate	complex
Cost	US$ 2.00 (without confirmation)	not available	US$ 14.00 (also detects T. Pallidum and HSV)

[1] The sensitivity of culture varies depending on the type of medium used and can only be estimated since there is no gold standard on which to base the diagnosis of chancroid.
[2] Resolved sensitivity of PCR vs *H. ducreyi* culture.

Table 10: Characteristics of HPV detection assays

	Cellular morphology	High-risk HPV DNA detection		
		Hybrid Capture	*In situ hybridization*	*PCR*
Sensitivity	62%-85%[1]	74%-93%	60%-80%[2]	80%-100%[3]
Specificity[3]	33%-96%	64%-68%	80%-90%	40%-61%
Advantages	detects HPV infection/disease	objective	confirm equivocal histological evaluation	very sensitive
Disadvantages	false-negative results, expertise required	no cellular morphology	labour-intensive, low sensitivity	low specificity for disease
Level of use	intermediate lab, referral lab	intermediate lab, referral lab	referral lab	referral lab
Training	extensive	moderate	extensive	extensive
Equipment	light microscope	water bath, shaker, luminometer	oven, slide incubator, light microscope	heat block, microcentrifuge, thermal cycler, microwell plate reader
Ease of performance	difficult	moderate	complex	complex
Cost	US$ 7.00-8.00	US$ 22.00	US$ 26.00	US$ 8.00

[1] Sensitivity is for detection of biopsy-confirmed high-grade dysplasia.

[2] Sensitivity is for detection of HPV in tissue confirmed by PCR amplification.

[3] Specificity is for detection of biopsy-confirmed high-grade dysplasia.

***Table 11:* Characteristics of HIV detection assays**

	Antibody detection		Antigen detection	DNA detection	RNA detection
	EIA	*Dot*		*PCR*	*Quantitative*
Sensitivity	100%	100%	detect earlier than antibody tests	as sensitive as culture	earliest detection
Specificity	95.8%-100%	99%-100%	100%	100%	100%
Advantages	sensitive, inexpensive automated	sensitive, specific, differentiate HIV-1 and 2	early detection	perinatal diagnosis, sensitive	monitor HIV levels
Disadvantages	false-positive results, no serotyping	expensive	insensitive	expensive, time-consuming	expensive, time-consuming
Level of use	intermediate lab	on-site lab, intermediate lab	referral lab	intermediate lab, referral lab	referral lab
Training	moderate	minimal	moderate	moderate	extensive
Equipment	centrifuge, microwell plate reader	none	centrifuge, microwell plate reader	microfuge, thermal cycler, microwell plate reader	depends on method[1]
Ease of performance	moderate	easy	moderate	moderate	extensive
Cost	US$ 2.00-3.00	US$ 6.00-7.00	US$4.00-5.00	US$ 12.00	US$ 60.00

[1] For RT-PCR: microfuge, thermal cycler, incubator, microwell plate reader. For bDNA: ultracentrifuge, luminometer. For NASBA: microfuge, luminometer.

Source: WHO Regional Office for the Western Pacific. Laboratory Tests for the Detection of Reproductive Tract Infections (1999)

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