

Surveillance of Populations at High Risk for HIV Transmission



**World Health
Organization**

Regional Office for South-East Asia

2007

Module 6

Surveillance of Populations at High Risk for
HIV Transmission

Participant Manual

2007

Other HIV surveillance training modules of this series

Module 1 - Overview of the HIV/AIDS epidemic with an introduction to public health surveillance: participant manual

Module 2 - HIV clinical staging and case reporting: participant manual

Module 3 - HIV serosurveillance: participant manual

Module 4 - Surveillance for sexually transmitted infections: participant manual

Module 5 - Surveillance of HIV risk behaviours: participant manual

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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 Module 5: Surveillance of High risk Behaviours. This course is meant primarily for those involved in the planning and implementation of HIV surveillance in high risk populations. As a participant, you should understand the basic epidemiology of HIV/AIDS and public health surveillance.

Module structure

The module is divided into units. The units are convenient blocks of material for a single study session.

This module can also be used for self-study.

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

You will keep to yourself 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 can then again check your work.

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 words. The glossary also contains acronyms that you may not recognize.

Module summary

This module provides an introduction to surveillance in populations at high risk for HIV transmission, with a focus on South-East Asia.

Appendices

More information is provided in:

Appendix A, References and Further Reading Material

Appendix B, Glossary and Acronyms

Appendix C, Useful Links

Appendix D, Answers to Warm-Up Questions and Case Studies

Additions, Corrections, Suggestions

Do you have changes to suggest for this module? Is there other information you'd like to see? Please email us. We will collect your letters and email and consider your comments in the next update to this module.

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Overview

What this unit is about

This unit introduces the surveillance of populations at high risk for HIV transmission (or 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. A high risk group is at increased risk of HIV infection because of higher risk behaviours.

True

False

2. Which of the following groups are at high risk for HIV infection in the South-East Asia region?
 - a. sex workers
 - b. injection drug users
 - c. men who have sex with men
 - d. all of the above

3. 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

4. List the two sampling methods that are commonly used in HIV surveillance of populations at high risk for HIV transmission.
 - a.
 - b.

5. An example of a potential legal harm to members of high risk groups because of HIV surveillance activities is _____.

Introduction

What you will learn

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

- discuss the importance of surveillance in populations at high risk for HIV transmission in different epidemic settings;
- identify high risk populations in the South-East Asia region;
- discuss the advantages and disadvantages of different sampling approaches, especially in the context of surveillance among populations at high risk for HIV transmission;

- understand the special ethical issues of surveillance of populations at high risk for HIV transmission.

Background

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

Second-generation surveillance

Second-generation surveillance refers to activities outside of those that are generally considered to be a part of routine case surveillance, such as case reporting and sentinel sero-surveys. Second-generation surveillance uses additional sources of data to gain a more comprehensive understanding of the epidemic. It includes biological surveillance of HIV and other STIs, as well as systematic surveillance of the behaviours that spread them.

An integral 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 being involved in transmitting HIV or contracting HIV. The group may be identified by the following:

- the presence or absence of HIV infection
- the presence of risky behaviours that create transmission events
- an occupation or other socioeconomic status that can be associated with risky behaviours.

Populations at high risk for HIV transmission

Sometimes referred to as 'at-risk groups' or 'most-at-risk populations,' members of high risk groups are at increased risk of passing HIV on to others, or of contracting HIV from others. They are often important in establishing, accelerating or sustaining the HIV epidemic. Therefore, it is important to understand the impact that HIV has had within these groups. Throughout this training document we will refer to these groups as 'populations at increased risk.' In Asia, populations at increased risk include:

- sex workers and their clients
- injection drug users (IDUs)
- men who have sex with men (MSM)
- mobile populations and migrants
- out-of-school youth
- prisoners
- uniformed personnel

In this module we describe methodological aspects of working with sex workers, including female, male and transgender sex workers.

Populations at increased risk are most likely to get HIV infection first in a new epidemic. They are infected at higher prevalence than the general population. In other words, a

population at increased risk will become infected at a faster rate than people who are not members of a population at increased risk.

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

Table 1.1

Populations at increased risk discussed in Units 2-8

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

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. These behaviours, for instance, include:

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

HIV is then transmitted quickly to other members of these groups through their *networks* of sexual and injecting drug partners. For example, if 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* to other groups and the general population, since they can introduce HIV into these groups. For example, a client of an HIV-infected sex worker may get HIV infection. He may then have unprotected sex with his wife, infecting her. In this scenario, he has acted as a bridge, from which HIV infection has passed from the sex worker to his wife.

Epidemic states

Although it is important at all states, HIV surveillance in populations at increased risk is used differently at different *states* of the epidemic. This is illustrated in Table 1.2.

Table 1.2

Uses of HIV surveillance data in populations at increased risk at different states of the epidemic

Epidemic state	Situation	Uses
Low-level	<ul style="list-style-type: none"> • HIV has not reached significant levels in high risk groups. • HIV is largely confined to people within high risk groups who exhibit higher risk behaviours. 	<ul style="list-style-type: none"> • Early warning of a possible epidemic. • Triggers interventions to prevent HIV in populations at increased risk.
Concentrated	<ul style="list-style-type: none"> • HIV has spread rapidly in one or more high risk groups. • Epidemic is not well-established in the general population. 	<ul style="list-style-type: none"> • Monitor infection in populations at increased risk. • Monitor effects of intervention programmes on HIV prevalence and behaviours.
Generalised	<ul style="list-style-type: none"> • Epidemic has matured to a level where transmission occurs in the general population (not dependent on populations at increased risk). • Without effective prevention, HIV transmission continues at high rates in populations at increased risk. • With effective prevention, in general, prevalence will drop in populations at increased risk before they drop in the general population. For example, following a prevention campaign targeted at sex workers, surveillance should first find a decrease in STIs in the sex workers, then in male sentinel populations, and then in antenatal clinics. 	<ul style="list-style-type: none"> • Monitor for initial decreases in HIV prevalence in populations at increased risk. • Monitor effects of intervention programmes on HIV prevalence and behaviours.

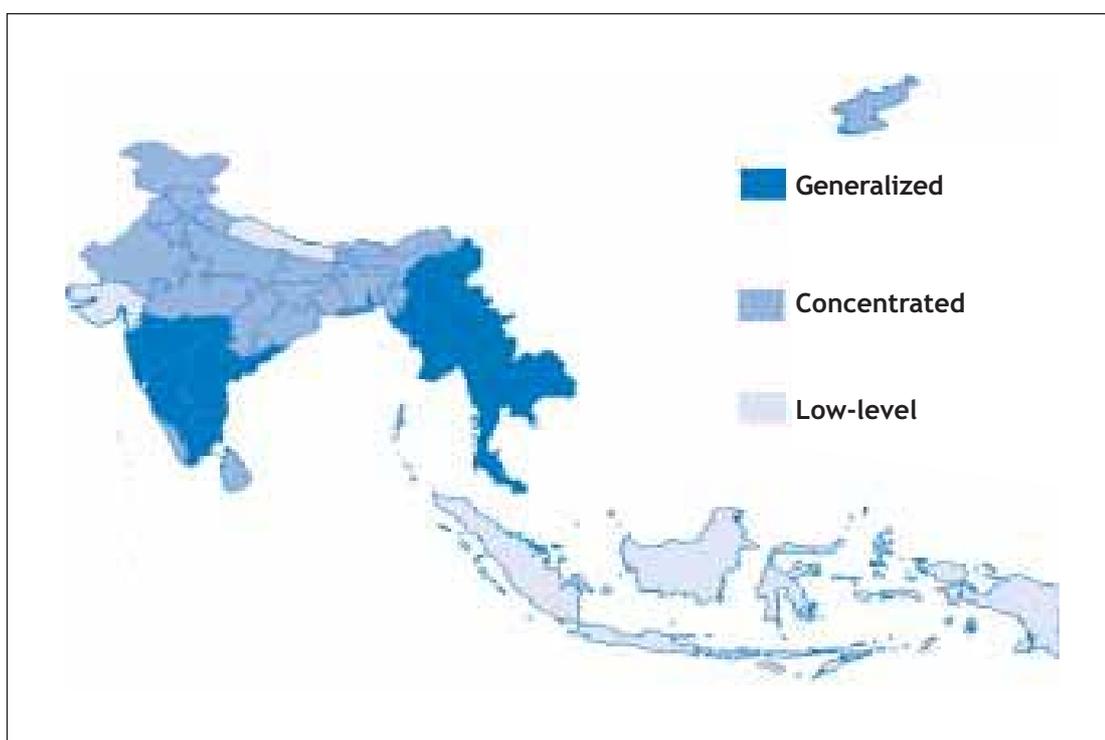
Figure 1.1 shows the state of the HIV epidemic in South-East Asian countries (next page).

Figure 1.1

State of the HIV epidemic in WHO-SEARO countries

HIV prevalence among various high risk groups

Surveillance in populations at increased risk has varied from country to country in the



South-East Asia region. Most countries have been relatively successful in gathering HIV surveillance data from female sex workers and STI clinic patients. Several have been able to conduct surveys among MSM, IDUs, prisoners, migrant populations and uniformed personnel. Examples are shown below.

- In India, national sentinel surveillance conducted in 2005 found that 8.4% of FSWs were infected with HIV.¹
- In 2005, data from sentinel surveillance revealed an HIV prevalence of 2% among FSWs in Kathmandu, Nepal.²
- In 2005, sentinel surveillance in Dhaka, Bangladesh found the prevalence of HIV among IDUs to be 4.9%.³
- In 2005, sentinel surveillance in Dhaka, Bangladesh found the prevalence of HIV among MSM to be 0.4%.⁴
- In 2005, sentinel surveillance found the prevalence of HIV among MSM in Kathmandu, Nepal to be 3.9%.⁵
- In Bangkok, Thailand, the overall HIV prevalence among MSM increased from 17.3% in 2003 to 28.3% in 2005.⁶

Pre-surveillance Activities

Conducting pre-surveillance activities is the first step in conducting behavioural and biological surveillance. Pre-surveillance activities include:

1. Identifying a co-ordinating body
2. Agreeing on the purpose of surveillance
3. Establishing criteria for selecting populations and geographic coverage areas
4. Gathering information to help with the decision about populations and geographic locations and to guide survey implementation
5. Finalising the selection of sub-populations and geographic locations for surveillance

Before conducting biological and behavioural surveillance in high risk populations, you should conduct formative research to gain an understanding of the populations, places and risk behaviours in which you are interested.

A pre-surveillance assessment is conducted to:

- identify key indicators to measure
- characterise the diversity of sub-populations
- determine the geographic areas and venues where at-risk populations may be found in high numbers.

The following three methods should be used for the pre-surveillance assessment:

1. Assess what is currently known about the national epidemic or sub-epidemic to identify potential hotspots and at-risk or vulnerable populations.
2. **Conduct pre-surveillance assessment using qualitative assessment methods and mapping** to further identify and verify hot spots. You should also gather information to clearly define the populations to be included in surveillance and to guide surveillance fieldwork.
3. **Gather information on risk behaviours and HIV levels in the general populations** to help validate whether the so called high risk populations are really at higher risk than the population at large.

Reviewing existing literature is central to conducting a pre-surveillance assessment. There are several sources of information that need to be reviewed, including the following: peer-reviewed scientific literature, abstracts from regional and international AIDS conferences, *grey literature* (literature that is not published in easily accessible journals or databases; for example, programme evaluations and governmental reports) and basic surveillance data.

Further information on how to conduct a pre-surveillance assessment is presented in Module 5: Surveillance of High Risk Behaviours.

Sampling Methods

Definitions

We sample when we desire to measure characteristics of a specified target population, but we lack the time and resources to obtain information from every member of the target population. For example, if we want to measure condom use among commercial sex workers in a capital city, but it is not feasible to question every sex worker about their behaviours, we select a sample to question. Table 1.3, on the next page, summarises the conventional sampling techniques.

Table 1.3

Summary of conventional sampling techniques

Sampling	Steps	Advantages	Disadvantages
Simple random	<ol style="list-style-type: none"> 1. Construct sample frame for survey population. 2. Select people randomly from sample frame using random number table or lottery draw. 	<ol style="list-style-type: none"> 1. Concept is easy to understand and analyse. 	<ol style="list-style-type: none"> 1. Requires sample frame of entire target population. 2. Logistically difficult if sample geographically dispersed. 3. Using random number/lottery time-consuming.
Systematic	<ol style="list-style-type: none"> 1. Construct sample frame for survey 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, etc. 	<ol style="list-style-type: none"> 1. Random numbers or lottery not required. 2. Easy to analyse. 	<ol style="list-style-type: none"> 1. Requires sample frame of entire target population. 2. Logistically difficult if sample geographically dispersed.
Stratified	<ol style="list-style-type: none"> 1. Define the strata and construct sample frame for each strata. 2. Take a simple/systematic sample from each strata. 3. Calculate indicator estimates for each strata and for population. 	<ol style="list-style-type: none"> 1. Produces unbiased estimates of indicators for the strata. 2. Can increase precision of indicator estimates. 	<ol style="list-style-type: none"> 1. Requires sample frame of entire survey population. 2. Logistically difficult if sample geographically dispersed. 3. Requires sample large enough to make precise estimates for each strata. 4. Population estimates require weighting.

Table 1.3

Summary of conventional sampling techniques, continued

Sampling	Steps	Advantages	Disadvantages
Cluster: Probability proportional to size (PPS) or equal probability sampling	<ol style="list-style-type: none"> 1. Construct sample frame of clusters. 2. Calculate SI, select random start between 1 & SI. 3. Select cluster whose cumulative size contains the random start. 4. Add SI to random start & select cluster. 5. Sample equal numbers of people from selected clusters. 	<ol style="list-style-type: none"> 1. Only need sample frame of clusters and individuals in selected clusters. 2. Sample concentrated in geographical areas. 	<ol style="list-style-type: none"> 1. Decreases precision of estimates; thus, requires larger sample size. 2. Size of clusters required prior to sampling.
Cluster: Equal probability, fixed cluster size	<ol style="list-style-type: none"> 1. Construct sample frame of clusters. 2. Select clusters using simple/systematic sampling. 3. Sample equal numbers of people from selected clusters. 	<ol style="list-style-type: none"> 1. Only need sample frame of clusters and individuals in selected clusters. 2. Sample concentrated in geographical areas. 3. Don't need cluster sizes prior to sampling. 	<ol style="list-style-type: none"> 1. Decreases precision of estimates; thus, requires larger sample size. 2. Weighted analysis required for unbiased estimates. 3. Size of clusters required for weighted analysis.
Cluster: Equal probability, proportional cluster size	<ol style="list-style-type: none"> 1. Construct sample frame of clusters. 2. Select cluster using simple/systematic sampling. 3. Sample equal proportions of people per cluster. 	<ol style="list-style-type: none"> 1. Only need sample frame of clusters and individuals in selected clusters. 2. Sample concentrated in geographical areas. 	<ol style="list-style-type: none"> 1. Decreases precision of estimates; thus, requires larger sample size. 2. Size of clusters required for proportional sampling. 3. Sample size; thus, precision of estimates unpredictable.

(Continued)

Newer Sampling Methods

Two new sampling methods combine the methods of *probability* and *non-probability sampling* to identify with relative ease 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

In *snowball sampling*, investigators seek out potential participants referred to them by current participants. 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.

Most studies will survey only the accessible or visible part of a group and miss those that are more hidden. For instance, a survey of sex workers working in bars and on the street in the red light district of a city will miss those sex workers who work at home, in other areas of the city and in brothels. Even snowball samples where sex workers refer their peers for up to six rounds (that is, one person will refer other people who will refer other people, up to six rounds of referrals) will not result in the entire population of sex workers being sampled, because not everyone will necessarily know each other. In other words, not all sex workers will be part of the same network. This type of network-based sample can lead to biased samples.

RDS overcomes this problem by combining how well network-based samples recruit people in the network with standard probability sampling methods. This makes it possible to draw statistically valid samples of previously hard-to-reach groups. In essence, respondents recruit their peers, as in network-based samples, and researchers keep track of who recruited whom and their numbers of social contacts. A mathematical model of the recruitment process then weights the sample to compensate for recruitment patterns. A greater description of the methods and statistical tests used in respondent-driven sampling can be found at www.respondentdrivensampling.org.

In the sex worker example mentioned above, a respondent-driven sample would choose one sex worker to start with. She would refer three—and only three—of her co-workers, and receive a small incentive for each referral. Each of her co-workers would, in turn, refer three of their co-workers, and so on for six or more rounds. Survey staff would ask each person in the survey how many people they know who work in sex work, while drawing blood or asking behavioural questions. Based on the knowledge of how many people each person knows, a picture of the entire network can be assembled based on random recruitment within the network. Using the respondent-driven sampling method, an overall estimate of, for instance, HIV prevalence, can be made with a minimum of sampling bias.

Time-location sampling

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. Time-location sampling is like conventional cluster sampling, but addresses the problem of everyone in the target population not being in the same place at the same time, because clusters are defined by both location and time. This strategy 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.

Preparing the sampling frame involves first creating a list of all places (or venues) where the members of the target population congregate (for instance, in brothels). The second part of preparing the sampling frame is figuring out at what times the target population congregates at these locations. As an example, if brothels were open seven evenings per week from 8PM to 4AM, and if there were 20 brothels in a city, there would be 7×20 —or 140—time-location sampling units. If the sex workers who worked from 8PM to midnight were different from the sex workers who worked from midnight to 4AM, we could also divide the time frame into two halves, from 8PM to midnight and from midnight to 4AM. We would then have $7 \times 20 \times 2$ —or 280—time-location sampling units. These units are essentially clusters.

Once the time-location clusters are defined, some numbers are selected randomly. The number needed will depend on the number of persons in the target population in each time-location cluster and how large the sample size needs to be. For instance, we could choose 30 time-location clusters. Once the sample of clusters is chosen, people in the clusters can be chosen for interview by various means. Some examples are:

- ‘take-all’ approach, in which all persons in the cluster are asked to participate
- random sample of persons in the cluster.

If clusters are of different sizes or if the target population has been enumerated, probability proportional to size methods may need to be used to ensure that larger clusters contribute more people to the sample (see Appendix 1.1). Time-location sampling can be further refined by using different strata. For instance, you could include one sample of casual sex workers and one sample of direct sex workers.

Comparing RDS and TLS

The sampling steps and the advantages and disadvantages of time-location and respondent-driven sampling are summarised in Table 1.4.

Table 1.4

The advantages and disadvantages of time-location and respondent-driven sampling

Sampling	Steps	Advantages	Disadvantages
TLS	<ol style="list-style-type: none"> 1. Calculate the required sample size. 2. Identify clusters through ethnographic mapping. 3. Construct a sample frame of clusters, defining clusters by both location and time if the population is floating. 4. Select clusters and individuals in clusters using PPS or equal probability sampling. 	<ol style="list-style-type: none"> 1. Allows us to do a probability sample of populations that are hidden or floating. 2. Only need sample frame of clusters and individuals in selected clusters. 3. Sample concentrated in geographical areas. 	<ol style="list-style-type: none"> 1. Mapping and ethnographic work can be time-consuming and clusters/sites can close rapidly. 2. Only reaches subsets of population that come into contact with the locations where sampling occurs. 3. Difficult to identify and access respondents. 4. Difficult to maintain randomness while selecting respondents within clusters. 5. PPS not often done due to difficulties estimating cluster size; samples often require weighting. This is not always done, which results in biased estimates.
RDS	<ol style="list-style-type: none"> 1. Start with initial contacts or 'seeds' who are surveyed and then become recruiters. 2. Each recruiter invites up to three people they know in the high risk group to be interviewed. 3. The new recruits become the recruiters. 4. Five to six recruitment waves occur. 	<ol style="list-style-type: none"> 1. Ease of field operations. 2. No need for ethnographic mapping or sampling frame. 3. Target population recruits for you; good when the group does not trust surveillance workers. 4. Less visible members of the population reached. 5. Lower cost. 	<ol style="list-style-type: none"> 1. Population must be a network. 2. Need to keep track of links between recruiters and recruits. 3. Ethical issues involved in using incentives. 4. Requires strong assumptions. 5. Still in experimental stage. 6. Special analyses.

Sampling approach criteria

You should assess sampling options for each high risk group of interest. Answering the following questions can help guide the selection of sampling strategies.

1. Is the population of interest the general population or youth? If **yes**, conventional cluster sampling is recommended.
2. Do group members congregate in accessible locations/sites in high proportions? If **no**, RDS is recommended.
3. Is it possible to construct a list of all group members associated with each site? If **no**, TLS or RDS is recommended.
4. Are all group members on the list (not just those who happen to be present at a site) readily accessible during data collection? If **no**, TLS or RDS is recommended.

Conventional household or institutional survey methods are feasible only when answers to questions 2-4 are “yes,” (and also feasible for the general population and youth). These questions are represented diagrammatically in Figure 1.2.

Detailed information on the sampling and survey methods available for conducting surveillance among high risk groups is provided in Module 5: 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.

The CDC Global AIDS Program (GAP) surveillance team is 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 by the CDC-GAP and WHO regional offices. The sampling selection tool will provide:

- An interactive, branching decision tree that includes detail on sampling design
- Supporting resources that may not be readily available, such as:
 - a bibliography with downloads or links to studies that have used various sampling designs
 - comprehensive information on populations at increased risk for HIV transmission
 - details of sampling designs.

Sample size calculation

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

Measures and Indicators

Behavioural surveillance indicators should measure behaviours that are key 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, number and types of sexual partners)
- behaviours that increase the chance that HIV will be transmitted if contact with an HIV-infected person occurs (for example, condom use or sharing needles).

The selection of indicators for surveying high risk groups should be determined by the country's data needs. Essential indicators for the sex workers, injection drug users and the general population are shown in Table 1.5.

Further information and the specific wording and precise definitions of questions and indicators that are used internationally can be found in Module 5: 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.ungass.org/index.php/ungass/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 key to the spread of HIV among FSWs. These guidelines are available online at: <http://www.fhi.org>.
- 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 online at: http://www.measuredhs.com/hivdata/ind_tbl.cfm.

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 research 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.

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

Table 1.5

Essential indicators for behavioural surveillance in injection drug users, female sex workers and men who have sex with men

Injection drug users	Female sex workers	Men who have sex with men
<ul style="list-style-type: none"> • Proportion who shared needles last time. • Proportion who did not use clean needles consistently in past week (or other time reference period). • Proportion who shared drugs. • Proportion who used condoms. 	<ul style="list-style-type: none"> • Last time and consistent condom use with clients. • Proportion who injected drugs in past year. 	<ul style="list-style-type: none"> • Proportion who used a condom the last time they had sex with a male partner. • Proportion who have had sex with more than one male partner in the past year.

Further information on the behavioural measures used in surveillance of high risk groups is provided later in this module and in Module 5: Surveillance of High risk Behaviours.

Biological measures

There are a number of choices to make about which biological measures to use in surveys of high risk groups. First and foremost is the choice as to 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 based on type of HIV transmission

Type of transmission	Infections to test for
Sexual	<ul style="list-style-type: none"> • syphilis • gonorrhoea • chlamydia • hepatitis A • herpes simplex virus type 2 • trichomoniasis • <i>H. ducreyi</i> (chancroid) • <i>T. pallidum</i>
Parenteral (blood-borne)	<ul style="list-style-type: none"> • hepatitis C • human T-lymphotropic virus type 1 (HTLV-I) • syphilis

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

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

Sexually transmitted infections

When high risk groups are at risk because of sexual transmission of HIV, rates of acute STIs are often used as a proxy for the presence of behaviours that could result in the transmission of HIV. Persons whose sexual risk is high enough to acquire an STI may also acquire HIV if they are exposed to it. Moreover, STIs are often more common than HIV, making studies more convenient than HIV prevalence surveys. They can serve as an early warning sign, because STIs are often present in a population before HIV enters it. In practise, because HIV cohort studies are expensive and logistically complicated and because HIV incidence measures are not widely available, monitoring and evaluation of the success of HIV prevention programmes often relies on STI incidence and prevalence.

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

- sex workers
- STI clinic patients
- men who have sex with men
- mobile populations and migrants
- prisoners
- uniformed personnel.

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

Testing for STIs

STIs that are most frequently measured are:

- syphilis
- gonorrhoea
- chlamydia
- herpes simplex virus type 2
- hepatitis A
- trichomoniasis.

In Asia, hepatitis B virus (HBV) is often acquired in childhood, and is thus a less reliable marker for injection drug use than it is in other regions.

Depending on the organism, a positive test 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, especially in women, testing is necessary.

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)
- herpes simplex virus type 2
- hepatitis A (IgG).

Serological tests for syphilis, herpes simplex virus type 2 and hepatitis A require blood samples. While antibody tests for chancroid can be done, they are not widely available.

Gonorrhoea and chlamydia can be detected in either urine or genital swabs (urethral swabs in men, which are rarely done, and endocervical or vaginal swabs in women). Often, because of the ease of collection of urine for detection of gonorrhoea and chlamydia, these infections are measured in hard-to-reach groups.

Syphilis is diagnosed serologically, and high-titre syphilis (for example, a positive specimen with a titre of 1:8 or higher) is an especially 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 being measured must be able to bring in participants back for treatment and for management of their sexual contacts.

Parenterally transmitted infections

Groups at high risk for parenterally acquiring HIV, such as injection drug users, have increased risk of other blood-borne infections. Hepatitis C virus is the blood-borne infection most typically measured.

Hepatitis C can be measured using a variety of laboratory tests, but is most often measured using a simple EIA. As with HIV, antibodies will be present for long periods of time—often decades—for most patients with hepatitis C. 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) is often used as an extra test for hepatitis C.

In addition to these antibody and antigen tests that detect specific infections, it is possible to screen for liver damage—an indirect marker of current or past hepatitis—using liver function tests, most commonly alanine-leucine transferase (ALT) and less commonly aspartate aminotransferase (AST). Note that ALT can be elevated in persons with alcoholic damage to the liver, though it is more prominent with AST.

The full range of available tests is shown in Appendix E: Laboratory tests available for measuring biological outcomes among high risk groups.

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

Ethical Considerations

High risk groups are often not included in regular surveillance activities because they can be difficult to reach. Because they are not included, there can be large gaps in our knowledge of the HIV situation in a country or district. To have the most accurate picture of the HIV epidemic, it is essential to understand the spread of HIV in high risk groups. Additionally, surveillance data can contribute to advocacy for improved care and treatment for these vulnerable populations.

Potential harms

Many high risk groups are marginalised, and sometimes their behaviour is illegal. High risk groups who have a legitimate basis to fear reactions of the larger society include the following:

- sex workers
- injection drug users
- men who have sex with men
- prisoners.

However, some level of risk probably exists for all high risk groups. A list of potential harms is listed in Table 1.7

Table 1.7

Potential harms caused by HIV and behavioural surveillance in high risk populations

Type of harm	Examples
Physical	Public attack, abuse, loss of healthcare services.
Psychological	Depression, suicide.
Legal	Arrest, prosecution.
Social	Disclosure to family, workplace discrimination, loss of employment, isolation.

WHO ethical guidelines

In 2003, WHO published a set of guidelines specifically directed at the 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
- data use and dissemination
- right to access test results.

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, stigma or even 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 around age of legal adulthood, including when adolescents can consent to participate in studies
- laws prohibiting sex work or sex work under a certain age
- 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.

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 them is part of the *informed consent* process.

Informed consent

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

Whenever informed consent is obtained, participation bias is an important issue. It may be useful to add a check box on consent forms to indicate those who choose not to participate in order to assist evaluation of participation bias. If this is not possible, other means of collecting information on non-participants can be incorporated in the data collection process.

Written consent forms and surrogate consent

Written consent forms are generally required to document that the process of informed consent has occurred. The appropriate reading level of consent forms is eighth grade level or lower. When literacy is low, consent can be obtained verbally. In that case, verbal consent needs to be documented. Examples of written and a verbal consent forms are included in Annex 1.2. For suggested wording and language for the specific elements that are required in consent forms, please refer to the CDC website: www.cdc.gov/od/ads/docs/consent.pdf.

When subjects are not capable of giving informed consent, either in writing or verbally, 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 may also have laws and standards about the age at which an adolescent can participate in research without their parents' consent. You should familiarise yourself with these laws in your country before you start the survey.

Although potential participants in surveillance and research activities are informed that participation in these activities is entirely voluntary, some groups may feel coerced into participation. Prisoners and potentially lower ranking members of uniformed services are especially vulnerable to the belief that if they don't participate they will be punished. In these situations, measures must be taken to ensure that effective communication and understanding is involved in the informed consent process.

Further information on the ethical issues related to surveillance of high risk groups is provided in Units 2 through 8.

Summary

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

In South-East Asia, populations at increased risk include female sex workers, injection drug users, men who have sex with men, mobile populations, out-of-school youth, prisoners and uniformed personnel. Many populations at increased risk are vulnerable to a variety of social factors, and as a result, surveillance and special studies in these groups raise several ethical issues. There are several conventional probability sampling methods that can be used for sampling populations. As many populations at increased risk are hard-to-reach sections of population, respondent-driven sampling and time-location sampling are ideally suited for surveys of high risk 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 the following questions.

1. In your country, what populations are most at risk of acquiring HIV?
2. Does your country conduct HIV surveillance among these populations? If yes, how frequently?

Notes

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. For example, you would like enough sex workers 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:

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

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 the factor of D. The design effect accounts for the similarities people have when they are sampled within the same cluster. For example, female sex workers within a particular brothel may be similar with respect to condom use because of the social norms, condom availability or intervention programmes of the particular brothel. Choosing a design effect is difficult without prior survey data. Design effects from 1 (that is, none) to 2 (moderate) cover a typical range. For RDS surveys, a small design effect of 1.25 is recommended. For cluster sampling and TLS, a moderate design effect of 2.0 is 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. For example, you wish to show that condom use at last paid sex for sex workers 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 significant 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 (increase) or down (decrease) from year to year (a “two-tailed” statistic). ***The smaller the significant level (that is, higher 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 (increase) or down (decrease) from year to year (a “two-tailed” statistic). ***The higher the power, the larger the sample size you will need.***

The table below provides pre-calculated sample size estimates for a range of possible scenarios in behavioural and sero-surveillance.

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 1.25 and 2.0.

Indicator level in wave 1 (P_1)	Indicator level in wave 2 (P_2)	Sample size needed each wave with a design effect of 1.25	Sample size needed each wave with a design effect of 2.0
0.10	0.20	247	395
0.10	0.25	123	197
0.20	0.30	363	581
0.20	0.35	171	274
0.30	0.40	441	706
0.30	0.45	201	322
0.40	0.50	480	768
0.40	0.55	214	343
0.50	0.60	480	768
0.50	0.65	210	336
0.60	0.70	441	706
0.60	0.75	188	301
0.70	0.80	363	581
0.70	0.85	149	239
0.80	0.90	247	395
0.80	0.95	93	149

Annex 1.2 Examples of Verbal and Written Consent to Participate in a Survey

Example 1a: Verbal consent form (not requiring a written signature)

University of Serosia

Information sheet for research participants

Purpose and background: The University of Serosia is conducting a survey of injection drug users. Participants will undergo a behavioural interview, receive monetary compensation for cost associated with their participation and obtain referrals for HIV prevention counselling and testing. The interview will assess sexual behaviours, drug use, condom use, experiences of discrimination and HIV/STI testing and other HIV and STI related behaviours with both standard and site-specific measures. This study will be based on data from 320 IDUs recruited from social and sexual networks in Indam, Serosia. You have been asked to participate because you were referred to the study by a person in your social or sexual network.

Procedures: If you agree to participate, the following will occur:

- You will be interviewed for approximately 45 minutes.
- You will be asked about:
 - your use of alcohol or other drugs
 - sexual activities
 - experiences of discrimination
 - condom use
 - knowledge of STIs and HIV
 - utilisation of local prevention programmes
 - demographic information.

Risks/Discomforts: This survey is totally anonymous, and no information identifying you will be collected. All the information we will ask of you has to do with your behaviour. **You can refuse to answer any question.** The information collected will be pooled with information provided by other people. Some of the questions might be considered intrusive or rude in a normal conversation, but are standard questions about infectious diseases and behaviours that transmit these infections. As such, some of the questions may make you uncomfortable for a short time. All data will be kept in locked files accessible only to the study personnel.

Benefits: There are no personal benefits to participating in this study. However, your knowledge and perceptions will be important to developing a better understanding of IDUs and the IDU community in Indam. This information maybe helpful in creating HIV prevention programmes for FSW in your community.

Reimbursement: At the end of the interview, you will be reimbursed 100 Serosian rupees (US\$2) in cash for costs associated with participating in this study. You will also be offered the opportunity to refer three more people to the study. If these people participate in the study, you will receive 50 Serosian rupees (US\$1) per person who participates. If you are one of the people recruited in the last wave of recruitment, you will receive 150 Serosian rupees (US\$3).

Questions: The interviewer has talked to you about this study and answered all your questions. If you have additional questions, you may contact the principal investigators at the University of Serosia.

If you have any comments or concerns about participation in this study, you should first talk with the investigators. If for some reason you do not wish to speak directly to them, you may contact Dr XXXXXX, Senior Lecturer, Department of Medicine, Indam Hospital 4th Floor, University of Serosia. His phone contact is XXXXXX.

Consent: Participation in research is voluntary. You are free to decline to be in this study, or to withdraw from it at any time. Your decision as to whether or not to participate in this study will have no affect on you. Similarly, you may refuse to answer any question or withdraw from the study at any time without any consequence to you.

You will be given a copy of this information sheet to keep.

Example 1b: Written consent form (requiring a written signature)

University of Serosia

Consent to be a research subject

A randomised trial of HIV prevention among injection drug users in Indam, Serosia

A. Purpose and background

Dr. XXX of the University of Serosia is conducting a research study to learn about ways to reduce transmission of human immunodeficiency virus (HIV) among injection drug users in Indam, Serosia. The purpose of this study is to compare two ways to do HIV-prevention health education for drug users at the venues where they receive medical and substance abuse assistance. You are being asked to participate in a group discussion as part of this study because you are a client, manager, doctor or staff member of an agency that provides services to drug users and receives funding from the National HIV Prevention Programme. The purpose of this group discussion is to gather your opinions about the programme, its implementation, its acceptability, and ways to improve the programme.

B. Procedures

If you agree to be in this study, the following procedures will happen.

1. We will ask you to come to a private place for a group discussion with 7-9 other participants. The discussion will be tape recorded and written down at a later time (transcribed).

2. You will be asked to respond to questions about your experiences with the National HIV Prevention Programme, your opinions about it and how, if at all, it has influenced you personally.

The discussion will take approximately two hours.

C. Risks and Discomforts

During this group discussion, other participants will hear what you have to say. We will ask you some personal questions that may cause you to feel embarrassed or awkward. You are free to refuse to answer any questions you do not wish to answer and you may leave the discussion at any time.

Confidentiality: Participation in this discussion will involve a loss of privacy, but information about you will be handled as confidentially as possible. We will not reveal your full name to other participants and at no time during the group discussion will your name be written down in connection with the information you have provided. We will ask you to use only your first name or to choose a fake name. We will also ask you and the other participants not to tell anyone outside of the group what any person said during the discussion. However, we cannot guarantee that everyone will keep the discussions private. Study records will be kept as confidential as possible. All tapes and transcripts of the discussion will be kept in locked filing cabinets and only members of the study team will have access to them. Your name or any other data that might identify you will not be used in any reports or publications resulting from this study.

D. Benefits

There will be no direct benefit to you from participating in this study. However, by taking part in this study, you will be helping the investigators learn about the best ways to promote HIV prevention among drug users who receive services from de-addiction and methadone maintenance programmes in Indam, Serosia.

E. Costs

There will be no cost to you as a result of taking part in this study.

F. Payment

You will not be paid to participate in this study. However, after you complete the focus group discussion you will be offered a small gift as a token of appreciation for your time. You will also be reimbursed for your transport costs to the place where the group discussion takes place.

G. Questions

This study has been explained to you by Dr XXX, Dr XXX or the person who signed below and your questions were answered. If you have any other questions about the research, your rights as a research subject, and/or research-related injuries, you may contact Dr XXX at 123 College Road., Indam, Serosia, (telephone XXX).

If you have any comments or concerns about participation in this study, you should first talk with the researchers. If for some reason you do not wish to do this, you may contact Professor XXXX at the Biomedical Research and Training Institute, which is concerned with the protection of volunteers in research projects. You may reach Professor XXXX at XXX. The address is 123 College Road, University of Serosia, Indam.

H. Consent

You will be given a copy of this consent form to keep.

YOUR PARTICIPATION IS VOLUNTARY. You are free to decline to be in this study, or to withdraw from it at any point. Your decision as to whether or not to participate in this study will not jeopardise your eligibility for future studies.

If you agree to participate, you should sign below.

Date

Signature of study participant

Date

Signature of person obtaining consent

Notes

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 female sex workers (FSWs) 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. List two places where direct SWs (SWs who work exclusively in sex work and have no other occupation) can be found.

- a.
- b.

3. _____ SWs do not engage in sex work full time, and may have another source of income. They are also called casual SWs or clandestine sex workers.

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

True

False

5. SWs and their clients are often _____ to other high risk populations. For example, male clients of FSWs may transmit HIV to their wives and non-commercial sex partners.

6. Name a sampling method that could be used among highly mobile sex workers, such as those who do not work in fixed 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 SWs in the HIV epidemic
- describe options for sampling SWs
- describe the special ethical considerations associated with conducting HIV surveillance activities in SWs.

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, occurs everywhere in the world. Sex work includes many practises and occurs in a wide range of settings. Two broad categories are often used to describe sex workers: “direct” and “indirect.” The typical features of *direct* and *indirect* sex workers are shown in Table 2.1.

Table 2.1

Comparing direct and indirect FSWs

Direct sex workers	Indirect sex workers
<ul style="list-style-type: none"> • have little or no source of income outside sex work • are also called formal sex workers • can be found in brothels • can be found in high concentration in streets, hotels, bars and massage parlours • may work by special arrangement via phone 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 STI clinics to monitor routine STI screening and treatment • may identify themselves as a SWs. 	<ul style="list-style-type: none"> • are those who may have another source of income or do not engage in sex work full time • are also called casual sex workers, clandestine sex workers or informal sex workers • may provide sex services in places or 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 phone or internet • are unlikely to be included in registries or lists of SWs routinely screened at STI clinics • may not identify themselves as SWs.

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. For example, sex may be bartered for material needs, school fees or illicit drugs. This behaviour is called *transactional sex*. In some areas, persons who engage in transactional sex are not considered sex workers.

Throughout the world, men also buy sex from male sex workers and *transgendered* (that is, biologically male persons who present as females) sex workers. These populations are often 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). However, in other ways, surveillance among MSWs is very different from surveillance among FSWs. For example, the *formative research* phases should identify issues with accessing men who have sex with men (MSM) and tracking behaviours specific to male-male sexual practices. Surveillance measures and approaches to sampling male sex workers are also discussed in the unit related to men who have sex with men (MSM). You should keep in mind that MSM and MSWs are different; a male sex worker may not identify himself as homosexual.

Role of SWs in the HIV epidemic

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

- high number of daily clients, increasing the probability of exposure to HIV and STIs
- high *partner concurrency* (that is, having extensive sexual network connections to many persons at the same time increases the spread of HIV and STIs)
- high frequency of use of commercial sex by men in the population
- high levels of other STIs that enhance HIV transmission
- high levels of injecting drug use
- high frequency of sex under the influence of alcohol or drugs (often affecting the ability to negotiate condom use)
- high 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 partners, steady and non-steady, with whom they do not use condoms
- high levels of mobility and travel (for example, to areas of 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

In South-East Asia, the *prevalence* of HIV among SWs varies by country and region, as illustrated in the following data:

- In India, national HIV sentinel surveillance conducted in 2005 found that 8.4% of FSWs were infected with HIV.⁷
- In 2004, the HIV prevalence among FSWs in Bangkok was 4.3%, down from 8.5% in 2000.
- HIV prevalence among FSW in Yangon and Mandalay, Myanmar was 33% and 53.6%, respectively, in 2003.
- In 2005, data from sentinel surveillance found an HIV prevalence of 2% among female sex workers in Kathmandu, Nepal.⁸
- In 2004, a cross sectional survey conducted in Jakarta, Indonesia found that the HIV prevalence among transgendered sex workers was 22%, and was 3.6% among male sex workers.⁹
- In 2004, among 519 male sex workers tested from among four provinces in Thailand, 9.6% were found to be infected with HIV.¹⁰

Role of SWs in surveillance

SWs can play a critical 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, FSWs may be the first to be detected with HIV infection.
- FSWs 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 FSWs. For example, the results of consistent condom use may be detected first among FSWs.

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.

Bridges and overlap with other populations

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

Some groups of men become the clients of SWs more frequently than the general population. These include:

- truck drivers or persons in other occupations that require travel
- military personnel
- police officers
- STI clinic patients.

SWs also overlap with many other high risk populations covered in this module. SWs are found among IDUs, out-of-school youth 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. The often desperate conditions of being a refugee or involuntary migrant may force women to sell sex to survive. Therefore, SWs may include both migrants who later become sex workers and women and children who are trafficked for the purpose of sex work.

Conducting Formative Research

Pre-surveillance assessment

The first step in planning HIV surveillance in SWs is to gain an understanding of the population in your area through *formative research*. *Pre-surveillance assessment* activities are conducted to identify key indicators to measure, the diversity of the sub-populations of SWs and the geographic areas and venues where SWs may be found in high numbers. The aims of the pre-surveillance process include:

- agreeing on the purpose and uses of surveillance data for SW programmes
- defining who is an SW for surveillance purposes
- identifying a co-ordinating or decision-making body
- selecting sub-populations to include
- delineating the geographic coverage areas
- selecting which indicator variables to collect.

Consider where to find SWs

Surveillance requires gaining access to the full range of SWs sub-populations and areas. However, locating all areas where SWs can be found and gaining access to SWs within these areas can be challenging.

You can locate and gain access to SWs by:

- visiting the venues where they congregate
- interviewing and working with the persons who facilitate or regulate contact
- collaborating with organisations that provide services to SWs.

Because SWs are often socially marginalised or rigidly controlled or trafficked by their handlers, forming key alliances may be necessary to obtain surveillance data. Examples of key 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 sex worker advocacy groups
- national and international organisations that broadly advocate for women's interests
- rickshaw and taxi drivers.

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

Conducting ethnographic mapping

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

- the places where SWs can be found
- the time periods of high and low volume of business
- types of sex work and sub-populations of SWs in your area.

This comprehensive description is used broadly to guide where and when SWs can be found to be recruited for surveillance activities, and what 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 SW population in your area. This sampling frame provides the basis for some *probability-based sampling* methods (for example, *time-location sampling* and *multi-stage cluster sampling*).

The places where SWs congregate in large numbers include:

- brothels, hotels, bars, discos and massage parlours where direct sex work is known to take place

- hotels, bars, discos and massage parlours where indirect sex work may take place
- streets, parks, beaches, truck stops and other outdoor areas where sex workers congregate.

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

- 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 on different times of the day and during different days of the week or month
- for each bar, count the number of SWs in four-hour time periods on 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. For example, how many SWs are part-time compared to how many are full-time? How many are direct sex workers and how many indirect sex workers?

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 sex workers play in the HIV epidemic is thought to be relatively small. The ways in which they can be included in future surveillance activities is under research.

An additional component of formative research entails an assessment of how *networked*, or interconnected, sex workers are with each other in terms of the venues where they work and the types of sex work in which they are involved. For example, do brothel-based SWs interact with street-based or indirect SWs? Do female sex workers interact with male or transgendered sex workers?

Is there an SW registration system?

In some countries of South-East Asia, there are formal registration systems for SWs. The registration process is usually part of an ongoing programme for STI screening and treatment. Registries can be used as a sampling frame for SWs or incorporated into a more comprehensive sampling frame produced by ethnographic mapping.

Bear in mind that not all SWs are likely to be registered. Registries may not include the full range of SWs (direct and indirect) in an area. Examples of non-registered sex workers may include indirect sex workers or those who are very young, new to the trade, foreign to local conditions, working outside establishments or practicing sex work part-time. Furthermore, in some areas, HIV-infected sex workers are excluded from the registration system under the potentially false presumption that they would no longer engage in sex work.

Examine STI clinics

You may also identify SWs in large numbers at STI clinics.

- Some STI clinics are located in *red light districts*, or areas of concentrated sex work, and cater specifically to SWs.

- Other STI clinics do not specifically cater to SWs, but do include a high number of them among their patients.

If the clients of STI clinics are to be considered for SW surveillance, information on whether the female clients engage in sex work or not must be systematically and routinely recorded.

Selecting a Sampling Method

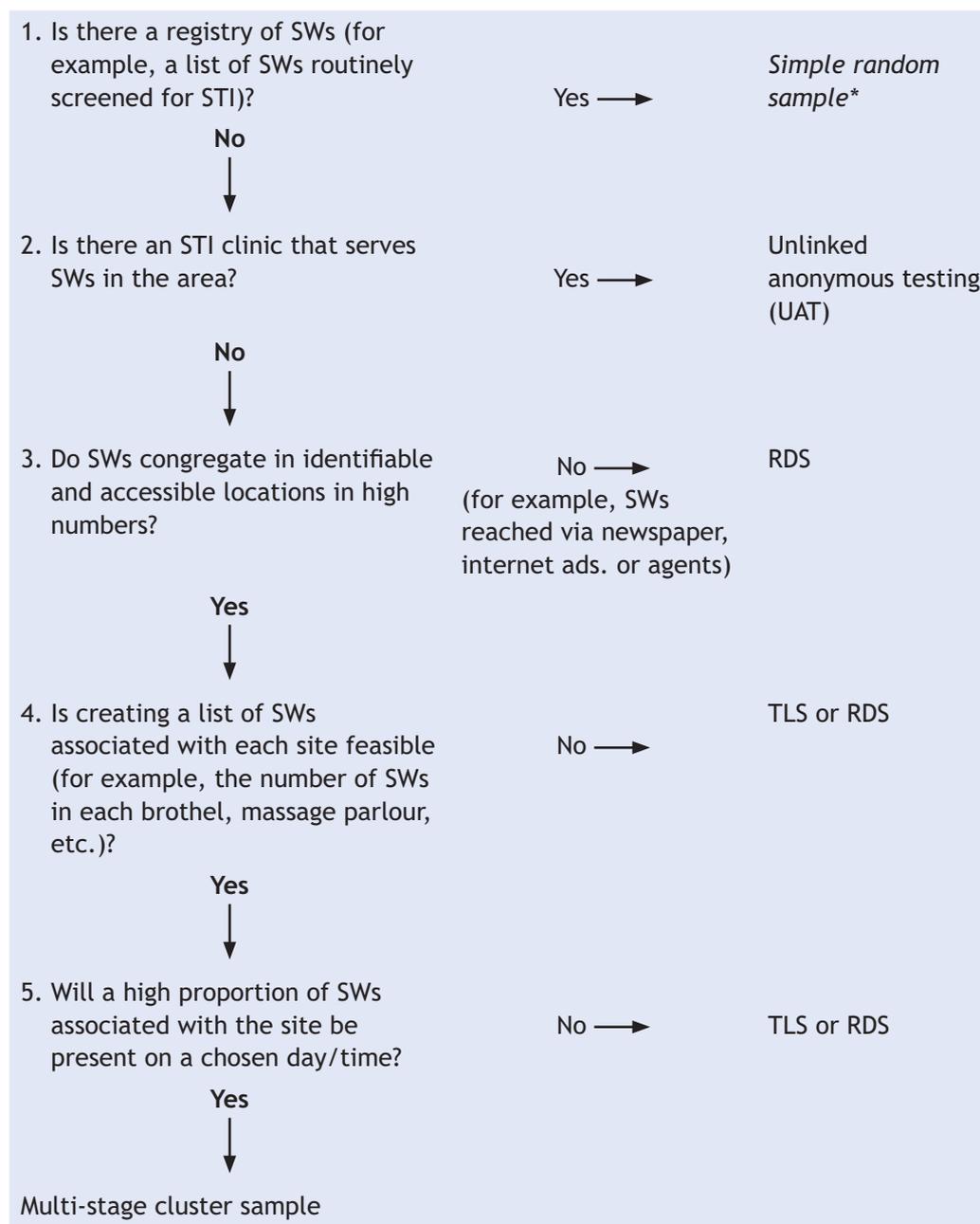
In the past, finding samples of SWs and other *hard-to-reach populations* were matters of convenience; and as such known as convenience or non-probability samples (for example, surveys of FSWs attending STI clinics, or interviews of the most visible FSWs found in certain areas). While non-probability samples can provide some information, these data can be biased for a number of reasons. For example, HIV prevalence and risk behaviours may be different in the most visible sub-populations of SWs, compared to those that are more hidden. There are probability and quasi-probability sampling methods now available that can be successfully 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 feasible. Several basic strategies for sampling hard-to-reach SW populations are:

- simple *random sample* from a registry (such as a registry of FSWs in a particular area)
- *consecutive sampling* via *unlinked anonymous testing* or 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 sex workers).

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

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 (for example, unregistered, indirect or highly mobile SWs). In addition, HIV-infected sex workers may be selectively excluded from such a registry.

Measures

Biological measures

Measuring HIV sero-prevalence among SWs is an integral component of surveillance. The high sexual risk among SWs also makes STI testing a useful and feasible indicator for surveillance (For a description of the available STI tests, refer to Appendix E: Laboratory tests available for measuring biological outcomes among high risk groups).

- *Syphilis* testing is often the most efficient biological indicator because the standard tests can be done with the same serological specimen as 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) testing is a marker for lifetime sexual risk. However, it is less available. To be an indicator for sexual risk, the test needs to distinguish HSV-2 from HSV-1.

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

In some parts of Asia, *hepatitis B virus* (HBV) is often acquired perinatally or from child to child contact in household settings, and may therefore be less of a marker for injection drug use than in other regions.

Behavioural measures

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

Several international organizations have sought to standardize a set of “core” or basic indicators of HIV risk among SWs. These include:

- percent of SWs who received HIV testing in the last 12 months and who know the results (UNGASS)
- percent of SWs who both correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV (UNGASS)
- percent of SWs reporting the use of a condom with their most recent clients (UNGASS)
- in response to prompting, correct identification of the use of condoms as means of protection against HIV infection (MEASURE)
- condom use during every episode of vaginal intercourse during the preceding three months (MEASURE)
- age of sexual debut (MEASURE)
- having been forced to have sex in the last 12 months (MEASURE)
- sex while intoxicated during the last 12 months (MEASURE).

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:

- sex work venues
- number of clients
- number of non-client sex partners, types
- condom use with non-client partners
- injection 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 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.ungass.org/index.php/ungass/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 key to the spread of HIV among SWs. These guidelines are available online at: <http://www.fhi.org>.
- 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 online at: http://www.measuredhs.com/hivdata/ind_tbl.cfm.

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 practices). The formative research 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

Because sex work is *stigmatized* 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*, inadvertent identification as an SW
- inadvertent disclosure of HIV status
- negative reaction and backlash in response to publicized 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 them. Explaining these issues to them is part of the informed consent process.

Step you can take to minimize 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 authorized study personnel only
- keeping study documents in a locked, limited-access room
- having all staff sign confidentiality forms and undergo training in research ethics.

Of note: the unlinked anonymous testing (UAT) methods preclude the disclosure of participants' names or other identifying information by design. Module 3: HIV Sero-Surveillance covers the methods of UAT in detail. In settings where confidentiality cannot be guaranteed and the potential harm of being identified as a SW or HIV infected person is severe, the UAT sampling method may be desired.

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 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 organized and how easily they are accessed, different sampling methods may be more or less feasible. 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 the following questions.

1. Does your country conduct behavioural and/or sero-surveillance of sex workers?
2. In your country, who are the gatekeepers of this population?
3. In your country, what methods are used to sample sex workers?

4. In your country, what behavioural and biological measures have been used when conducting surveillance of sex workers?
5. In the past five years, has the prevalence of HIV among sex workers 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 Brothel-Based Sex Workers In Tapang, Serosia

Part 1: Collecting information to plan surveillance activities

Tapang is a port city in Serosia with a total population of ten million. A large number of male workers from adjacent cities and provinces migrate to Tapang 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 20,000-30,000 sex workers in Tapang. It is believed that most of the sex trade in Tapang is brothel-based.

The annual HIV sero-surveillance data, published by the National AIDS Programme, Ministry of Health, Serosia, indicates that the HIV prevalence among sex workers has remained high in the past five years. Recently, the Kate Foundation, a philanthropic international agency, awarded a five-year grant of US\$ 2 million to Tapang Municipal Corporation for implementing prevention interventions among sex workers. 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, Tapang City, directs the HIV programme manager to develop a package of evidence-based interventions to reduce HIV transmission among sex workers.

The HIV programme manager decides to undertake a behavioural survey among brothel-based sex workers in Tapang. He holds a meeting with his team of epidemiologists and social workers to plan for the survey, particularly the following:

1. What information is required for planning the survey?
2. How will the Tapang HIV team obtain this information?

Part 2: Building key alliances with community networks involved with sex workers

To obtain background information for designing a behavioural survey, the HIV team reviews 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, pan shops, auto rickshaw drivers, police and NGO managers and outreach health workers. The HIV team collects information on how the brothel-based sex trade is operated, the location and number of brothels, the number of sex workers in each brothel, the business hours of sex workers, health services available in the area and NGOs operating in the area.

Using information from formative research, the HIV team maps the brothels in Tapang. It is noted that 80% of the brothel areas are concentrated in the southern part of the city named Redpura. There are approximately 80 brothels in Redpura. On average, there are 30 sex workers in each brothel. As commercial sex work in Serosia 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 underutilised due to the lack of availability of drugs. Sex workers frequently visit private practitioners for treatment of STIs and other ailments.

Since the majority of the brothels are concentrated in Redpura, the HIV programme manager decides to first undertake a behavioural survey among sex workers in Redpura. The HIV team realises that in order to access sex workers, 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 meets with NGO managers, brothel owners, agents, pimps, madams, auto drivers, hotel managers, bar owners and the police in the area.

A briefing meeting is organized 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 is now ready to move to the next step.

5. What are the possible approaches to conducting a behavioural survey among sex workers in Redpura?
6. What are the advantages and disadvantages of each approach?

Part 4: Choosing a sampling approach

The Tapang HIV team has two options: 1) to undertake a community-based survey at the workplace of sex workers (for example, brothels); or, 2) to undertake an institutional survey at the public health clinic where sex workers access treatment of sexually transmitted infections (STIs).

The team weighs the pros and cons of each approach. It is less expensive and logistically easier and quicker to use an institutional approach. However, the team feels that the reach of the public clinics is limited, as nearly three-fourths of the sex workers are utilising services from private practitioners in the area. It is more expensive to undertake a community-based survey. However, the findings of the survey will be more representative of all sex workers 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 decides to undertake a community-based cross-sectional survey of risk behaviours among brothel-based sex workers in Redpura.

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 FSWs from 20% in the current year to 35% if the survey is repeated in two years? (Refer to table with the sample size options).

Part 5: Collecting behavioural data

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

The surveillance team is able to obtain a reasonably complete listing of brothels in Redpura with the approximate number of FSWs in each brothel. This 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 sex workers are selected in each brothel by random sampling.

9. What behavioural variables should be collected?
10. What special ethical considerations need to be considered for this surveillance activity?

Part 6: Analysing and disseminating data

Note: While 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 sex workers at the selected brothels during non-business hours. They explain the purpose of the study to sex workers and obtain verbal consent. Confidentiality is assured. The 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 sex workers 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 Tapang City Public Health Commissioner.

- A total of 289 sex workers were interviewed. The mean age of respondents was 30.9 years; 20% were non-literate and 44% had a primary education. On average, each sex worker 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. However, respondents encountered 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 sex workers in Redpura were highly at risk of acquiring and transmitting HIV. Sex workers had a high partner turnover; a large proportion of them 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 sex workers in Redpura.

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

- engage peers and NGO outreach workers to educate sex workers about the need for consistent condom use with clients and regular partners
- conduct workshops to improve condom negotiation skills of sex workers
- distribute condoms to sex workers through peers and NGO workers
- 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 organises 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 Tapang 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 injection 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 in 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 organizations 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 must you consider when conducting surveillance in IDUs?

Introduction

What you will learn

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

- describe special considerations associated with HIV surveillance in 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 in *injection drug users* (IDUs).

Drugs injected by IDUs can 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 and obtaining and injecting drugs dominate the lives of these individuals.

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 transmission.

The use of non-injectable drugs, such as smoking marijuana, ingesting sedative-hypnotic drugs, inhaling cocaine, sniffing glue and drinking alcohol, cannot directly lead to HIV transmission. However, they can indirectly contribute to the problem of HIV, since they can be associated with the necessity of sex work in order to acquire funds to buy drugs, or with 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 injecting drug users then efforts must be made to accurately distinguish IDUs from other drug users. Screening for injection may occur at the facility level (for example, de-addiction clinics specifically for IDUs) 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.

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 may also inject a small amount of the previous user's blood that has remained behind 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* and *hepatitis C*. *Parenteral transmission* is the term that refers to blood-to-blood transmission, such as transmission through:

- transfusion of blood
- transfusion of blood products (for example, anti-haemophilic factors)
- needlestick injuries (for example, 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 are also at risk for sexual transmission of HIV, through sex work and through their regular partners.

In most regions of the world, injection 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 industrialized countries and those with middle-level incomes, including many in Asia. In some countries of South-East Asia, 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 epidemics once HIV is introduced. Such has been the case in the Indian states of Nagaland and Manipur and the countries of Myanmar, Thailand, Vietnam and Nepal, which are all located in or near one of the world's major opium-producing areas.

Parts of Myanmar, Thailand and Vietnam have all recorded very high levels of HIV infection among IDUs. In some places (including Myanmar, Thailand and Manipur), HIV infection rates have 'stabilised' among IDUs at levels between 40% and 60% for nearly a decade.

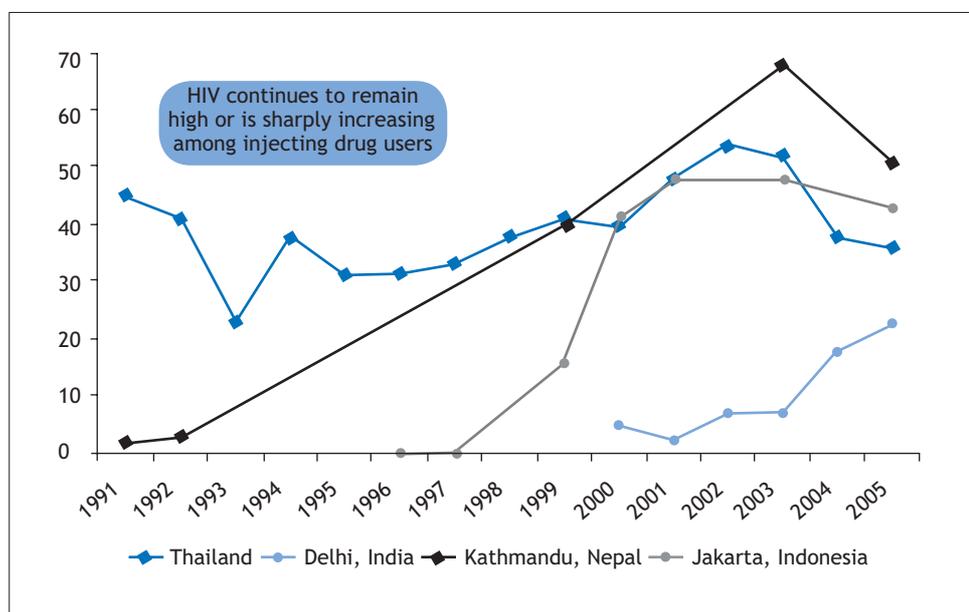
In South-East Asia, the prevalence of HIV infection among IDUs varies by country and region, including the following examples:

- nearly 50% of IDUs in treatment in Jakarta, Indonesia were living with HIV in 2003.¹¹
- in 2002, the prevalence of HIV among male injectors in Nepal ranged from 22% to 68%.
- in 2005, a national survey in Myanmar found an HIV prevalence of 43% among IDUs.¹²
- according to India's National AIDS Control Organisation, about 10% of HIV-infected people in India contracted the virus through injection drug use.^{13, 14}
- in 2005, 40% of IDUs in Chennai and 29% in Mumbai, India were infected with HIV.
- in Thailand, HIV prevalence among IDUs varied from 36% in Bangkok to 39% in Songkla Province to 50% in Chon Buri Province in 2005.

Parts of China, Indonesia and Vietnam have seen HIV take off among drug injectors in recent years, as shown in Figure 3.1.

Figure 3.1

HIV prevalence among injecting drug users in selected south-East Asian countries, 1991-2005



Note: Data unavailable for some years is reflected by dotted line

Source: National surveillance reports.

Role of IDUs in surveillance and bridges with other populations

In countries with substantial number of IDUs, HIV may first appear in the 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. Other IDUs may have sexual partners who are not IDUs themselves. Finally, the mothers of HIV-infected children are often female IDUs or female partners of male IDUs in countries with low-level and concentrated epidemics.

IDUs therefore overlap with many other *high risk populations* covered in this module. IDUs are found among *MSM*, prisoners, *out-of-school youth* and female sex workers. 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.

Conducting Formative Research

Pre-surveillance assessment

The first step in planning HIV surveillance in IDUs is to gain an understanding of the population in your area through *formative research*. *Pre-surveillance assessment* activities are conducted to identify key indicators to measure the diversity of the sub-populations of IDUs and the geographic areas and venues where IDUs may be found in high numbers.

The aims of the pre-surveillance process include:

- agreeing on the purpose and uses of surveillance data for IDU programmes
- identifying a co-ordinating or decision-making body
- selecting IDU sub-populations to include?
- delineating the geographic coverage areas
- selecting which indicator variables to collect (behavioural and biological)
 - determining the primary drugs used in the area
 - ascertaining whether there are any unusual drug preparations or use practises in the area (such as homemade drug solutions prepared with blood).

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 to more fully understand the culture and diversity of IDUs in your area.

Consider where to find IDUs

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 individuals 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. Persons to contact include the following:

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

These same people and organisations can also later assist in implementing surveillance activities. For example, former IDUs 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 may also 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 to be recruited for 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-based sampling* methods (for example, *time-location sampling* and *multi-stage cluster sampling*).

IDUs can be found in relatively large numbers at a variety of facilities. These include:

- 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.

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

Check at drug treatment centres or methadone maintenance programmes

Surveillance in IDUs has historically 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 (see Module 3: HIV Sero-Surveillance). Other countries have relied on IDUs who have been arrested and imprisoned, also using the UAT or *mandatory testing* approach. However, neither of these populations 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 VCT approach (for example, in India and Myanmar).

The illegal nature of injecting drug 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. Thus, 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:

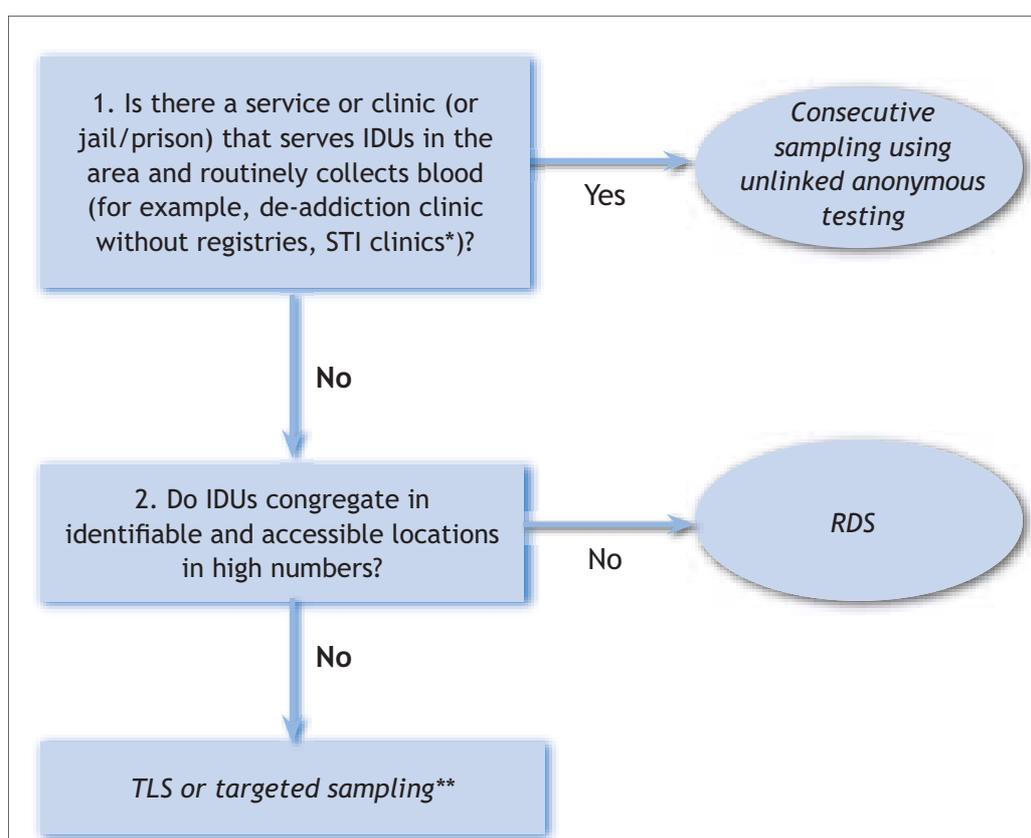
- consecutive sampling at treatment facilities, using unlinked anonymous testing
- consecutive sampling in jails and prisons, using unlinked anonymous testing
- *respondent-driven sampling* (RDS)
- time-location sampling (TLS)
- targeted sampling and targeted interventions.

All these sampling methods have advantages and limitations. Further details of these methods and their relative advantages and limitations are described in Modules 3: HIV Sero-Surveillance and Module 5: Surveillance of High risk Behaviours.

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 research, you have determined the relative size of the sub-populations of IDUs in the different areas. For example, if you know that 25% of IDUs in your area are youth who congregate near the beach, 30% are MSM in the city centre and 45% are in the red light district, you can target your sampling to locations in the neighbourhoods in these proportions.

Safety factors

Recruiting and/or 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 formative research you find that particular locations or times are too dangerous for data collectors, some sampling designs, such as time-location sampling, may not be feasible.

Measures

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 the following.

- Anti-hepatitis B core antigen (anti-HBc) is a non-specific marker of acute, chronic or resolved HBV infection. Anti-HBc is usually found in chronic HBV carriers, as well as those who have cleared the virus, and 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 those with weak immune systems, such as those with AIDS), chronic infection with HBV may occur when HBsAg remains positive.
- Hepatitis C (Test may be expensive).

Additionally, in Asia, HBV is often acquired parinatally or from child-to-child contact in household settings, and is thus not as reliable a marker for injecting drug use as it is in other regions.

IDUs are also at risk of HIV through sexual behaviour. Biological markers for STIs may also be considered in surveillance for IDUs (For a description of the available STI tests, refer to Appendix E: Laboratory tests available for measuring biological outcomes among high risk groups).

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 provides 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. The more frequent the sharing, the higher the risk. Some drugs may result in more frequent injection than others. For example, cocaine and methamphetamine injection 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.

In broad strokes, behavioural surveillance of 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. These include:

- the percent of IDUs who have adopted behaviours that reduce transmission of HIV (that is, who have both avoided non-sterile injecting equipment and used condoms in the last month (UNGASS)
- the percent of injecting drug users active in the last month who report sharing needles, syringes or other injecting equipment the last time they injected drugs (MEASURE)
- the percent of IDUs who received HIV testing in the last 12 months and who know the results (UNGASS)
- the percent of active injecting drug users surveyed who report never sharing injecting equipment during the last month (MEASURE)
- the percent of injecting drug users surveyed who used a condom the last time they had sex, of those who have had sex in the last 12 months (MEASURE)
- the percent of injecting drug users surveyed who used a condom the last time they had sex with a non-regular partner in the last 12 months (MEASURE)
- the percent of injecting drug users surveyed who used a condom the last time they had sex with a regular partner in the last 12 months (MEASURE).

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:

- injecting locations (for example, shooting galleries)
- frequency of injections
- types of drugs injected
- those with whom IDUs share needles and syringes
- size of social network
- condom use
- history of incarceration
- history of sex work
- contact with female sex workers.

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 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.ungass.org/index.php/ungass/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 key to the spread of HIV among IDUs. These guidelines are available online at: <http://www.fhi.org>.

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

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 practices). The formative research 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

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 backlash 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. 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, with severe penalties
- more severe penalties for those identified as dealing drugs
- laws requiring reporting of individuals 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 them.

Ensure interviewer safety

Conducting HIV surveillance among IDUs requires face-to-face contact with drug-dependant persons who may have criminal histories, psychiatric conditions and/or violent tendencies. These persons may pose a risk to the interviewer's safety. Interviewers should be trained on how to assess intoxication and how to ensure their own safety.

Summary

Due to unsafe injecting practices 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.

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 the following questions.

1. Does your country conduct behavioural and/or sero-surveillance of female sex workers?
2. In your country, who are the gatekeepers of this population?
3. In your country, what methods are used to sample injection drug users?
4. In your country, what behavioural and biological measures have been used when conducting surveillance of injection drug users?
5. In the past five years, has the prevalence of HIV among injection drug users in your country increased, decreased or remained about the same?

Apply what you have learned/case study

Behavioural surveillance survey among IDUs in Mandu, Serosia

Part 1: Collecting information to plan surveillance activities

You are the HIV surveillance officer for Mandu. Mandu is a medium-sized city in northern Serosia and a major transit point on the drug-trafficking route between Asia and Western Europe. There have been reports of increasing 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 a behavioural and HIV sero-survey of drug injectors in the city.

The police chief suggests that you start with prisoners who were convicted of trafficking heroin and test them.

With the help of prison personnel you conduct unlinked anonymous HIV testing using blood left over from syphilis testing that was done when each prisoner was initially incarcerated.

1. What are the advantages and limitations of this approach?
2. Describe the steps you take to conduct this survey. How do you ensure confidentiality?
3. What biological markers do you include?
4. How might HIV prevalence estimated from prisoners differ from IDUs outside of jails?

Part 2: Building key alliances with community networks involved with injection drug users

HIV prevalence among injectors in the jail is 5.5%. Only 20 injectors were under the age of 25 years. None were female, although the police indicated that many of the sex workers arrested are also injection drug users. No information was collected on needle-sharing or sexual behaviours.

5. Whom do you need to reach in order to measure HIV prevalence among IDUs? What questions do you need to ask them?

You determine that information gathered from jails is not sufficient to fully characterize all the injection drug use in the city. Your office decides to conduct formative research to describe both the young injecting network and other networks and sub-populations of IDUs.

6. Who are the key stakeholders and community groups with whom it is necessary to build alliances?
7. How will the HIV team engage the different stakeholders?

Part 3: Choosing approaches to combined behavioural and biological surveillance

The HIV surveillance team meets with key informants, including HIV prevention and care GO and NGO personnel, STI clinic and detoxification centre employees, taxi drivers, bar owners, police in the area and former IDUs found through NarcAnon-Asia.

A brief meeting is organised at which the HIV surveillance manager informs the stakeholders about the need for and purpose of combined behavioural and biological surveillance of IDUs in Mandu.

Using information gathered from stakeholders, the HIV team characterizes a wide range of injecting drug users. Three geographically distinct groups of IDUs are identified: 1) a group of young injectors who use heroin and congregate in the centre of Mandu, 2) a group of older injectors who congregate on the outskirts of town, and 3) a group of injecting brothel-based and street-based female sex workers who mainly congregate in Mandu's red light district. While the groups are geographically and socially distinct, you find that members of the three groups do mix to some extent.

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

8. What sampling schemes would be appropriate for conducting community-based sampling of IDUs in Mandu?
9. What are the advantages and disadvantages of using TLS vs RDS? Which one do you think will work best in Mandu?

Part 4: Implementing RDS

You decide that respondent-driving sampling (RDS) is the most feasible method for sampling IDUs in Mandu. As you have limited financial and human resources, you must accomplish the survey in three months.

10. Which individuals will you select as seeds? Why?
11. What kind of incentives will you give?
12. What are the ethical considerations of providing incentives?
13. What questions do you want to include in your survey?

You decide to plant a total of six seeds, with two seeds in each IDU network (young injectors, older injectors, injecting sex workers). The individuals 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, while the seeds you planted among the younger injectors and the injecting sex workers have grown, the two seeds you planted among older injectors have not grown.

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

Although you could replant your previous selected seeds or give your seeds more time to grow, since you have limited time and resources, you decide to re-sow and find two new older IDU seeds. The chains continue to grow and you are between one-third and halfway through the time allotted.

15. How will you know if equilibrium is met? What does this mean?

16. What variables will you follow to determine when equilibrium is reached?

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

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

Part 5: Analysis

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

18. What data analysis software do you use?

19. What variables did you need to have collected in order to analyse the data? Do you recall if you mentioned collecting these when planning the survey?

RDSTAT is the most appropriate analysis software for analysing your data. It is available free of charge online at: <http://www.respondentdrivensampling.org/main.htm>.

In order to analyse your data, it is imperative that you have data on each respondent's network size and by whom each respondent was recruited.

Part 6: Epilogue

The RDS-adjusted population estimate for HIV was 17.1%. Half of the IDUs were under the age of 25 years and one-fourth 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 of Mandu directs the HIV programme manager to initiate the following interventions:

1. Expand drug detoxification and treatment programmes in Mandu.
2. Establish a needle-exchange programme.

Notes

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 concerning MSM and specific study issues.

Warm-up questions

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

True

False

2. List two common points of access where MSM can be found.
 - a.
 - b.
3. Because 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?

Introduction

What you will learn

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

- describe the special considerations associated with surveillance in men who have sex with men
- list the possible organisations that 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* 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 engage in male-male sex who identify as heterosexual.

Another group that has historically been included in MSM are those 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. 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 well-defined 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 themselves 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 these MSM.

Role of MSM in the HIV epidemic

Men who have sex with men represent a substantial proportion of the Asian HIV epidemic. The HIV prevalence among MSM may be experiencing rapid increases. Additionally, some research indicates that bisexual activity is more common in Asia than in other parts of the world.

MSM can be exclusively homosexual and have sex only with men. They can also be bisexual and have sex with both men and women. When developing the sampling frame, it is important to note that in many societies, men who have sex with men may also 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 is what puts MSM at higher risk in general. Men who have sex with both men and women may represent an important *bridge group* between a sub-population at high risk for HIV infection and a larger population at lower risk for infection.

In Asia, marriage pressure (that is, the phenomenon of family pressure on sons to marry in order to provide stability for parents and the continuation of the family name) may be greater than in other regions. Marriage pressure may be a factor in the higher rates of bisexual behaviour seen in Asia.

Prevalence of HIV among MSM

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

* RDS= Respondent-Driven Sampling, TLS= Time-Location Sampling, CV= Convenience Sampling

** Not available

Role of MSM in HIV surveillance

HIV surveillance of men who have sex with men (MSM) is critical in all countries. Data throughout the developing world indicate increasing HIV prevalence among MSM populations. Overall, however, routine surveillance among MSM is sporadic at best, 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
<ul style="list-style-type: none"> • North America • Australia • New Zealand • Most Western European nations 	MSM are the most affected population
<ul style="list-style-type: none"> • Asia • Latin America 	Depending on the country, MSM may constitute a large proportion of persons affected by HIV
<ul style="list-style-type: none"> • Sub-Saharan Africa • North Africa • Middle East 	Little or no data exist on the burden of HIV among MSM

Bridges and overlap with other populations

In Asia, as in the rest of the world, a proportion of MSM also have sex with women. Some research indicates that MSM in Asia may have a higher proportion of bisexual behaviour than in other regions. The potential for MSM to *bridge* HIV infection to heterosexual women is an issue deserving monitoring and investigation. Surveys of MSM should always ask about all types and genders of partners MSM may have. MSM can also be members of other high risk populations covered in this module. MSM are found among IDUs, STI clinic patients, *out-of-school youth*, prisoners and sex workers. Being a member of two or more high risk groups increases HIV infection risk for MSM.

Conducting Formative Research

Formative research is necessary in order to characterise the range and diversity of MSM populations in the area of interest. Attention should be paid to the behaviours MSM engage in, their overlap with other *high risk populations* and their geographic concentrations. In addition, determining the extent to which MSM identify as gay or non-gay is crucial. This research will help to identify the various points of access and places where potential surveillance among MSM can be conducted.

Pre-surveillance assessment

Prior to beginning surveillance, you should conduct a *pre-surveillance assessment* to identify your data needs and determine which sub-populations and geographic locations to include.

Steps in the pre-surveillance process include:

- identifying a co-ordinating and decision-making body
- agreeing on the purpose of surveillance
- establishing criteria for selecting sub-populations and geographic coverage areas for surveillance
- gathering information to guide survey implementation and to help you decide which sub-populations and geographic areas to include in surveillance and which variable to collect
- finalising sub-population and geographic selection.

Consider where to find MSM

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

Surveillance activities should enlist the assistance of:

- health authorities
- social services
- MSM groups
- *gatekeepers*, such as gay activists and religious leaders
- organizations that represent MSM interests
- existing public health prevention programmes.

Surveillance officers should also enlist the support of those whom the community trust as sources of information. These individuals include:

- natural leaders of the MSM community (asking around can usually easily elicit names of MSM leaders)
- owners of MSM businesses/venues (such as saunas and bars)
- employees of MSM businesses/venues (such as bars, dance clubs, hair salons).

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.

A key 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 keys to choosing the appropriate sampling methodology.

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 to choosing a sampling method and for creating a sampling frame.

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

- restaurants
- gay-identified bars
- dance clubs
- gyms
- parks
- bathhouses
- social organizations
- other *cruising areas*.

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

Other points of access may be through gay newspapers, magazines or gay-focused services, clinics specialising in MSM health and internet chat rooms. In contrast, MSM venues in countries without well-developed gay communities will be more difficult to

identify. Some MSM do not congregate in particular locations. They may be deliberately elusive due to stigmatization of homosexual behaviour.

Organisations providing HIV prevention or AIDS care services to MSM should not be included as venues, as such inclusion has the potential to inflate estimates of HIV infection and/or HIV risk behaviour.

Selecting a Sampling Method

While surveillance of MSM may be more difficult than surveillance of female sex workers, the methods for approaching surveillance efforts are similar.

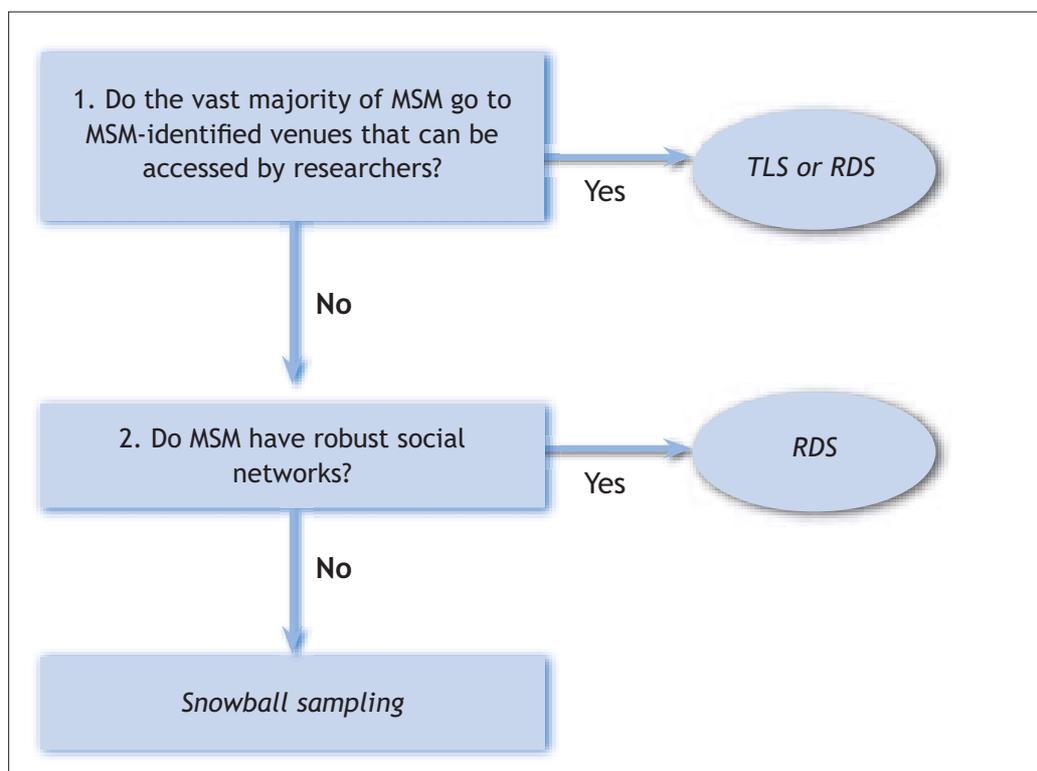
As with surveys of other hard-to-reach populations, getting a representative sample is difficult. There is no clear *sampling frame* and many studies have relied on various *non-probability sampling* methods. Because these samples are not representative, it is difficult to use them to compare indicators over time. Two methods that have successfully been used 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* may be the only appropriate method to use. Figure 4.1 on the next page will help you select an appropriate sampling method for MSM in your area.

Figure 4.1

Appropriate sampling methods for MSM



Male sex workers

In areas where MSM sell sex to other men, sampling techniques used for sex workers may be more appropriate and effective for this sub-population. Please refer to Unit 2 (Sex workers) for further information.

Measures

Comprehensive HIV surveillance among MSM includes surveillance of:

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

The ideal surveillance system should also 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 integral component of surveillance. The high sexual risk among MSM also makes STI testing a useful 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).

The biological measures to include in surveys of MSM are similar to those for female sex workers and may include:

- *syphilis*
- *gonorrhoea* (urethral, rectal and pharyngeal)
- *chlamydia* (urethral, rectal and pharyngeal)
- *herpes simplex virus type-2* (HSV-2).

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 may be expensive.

In Asia, hepatitis B virus (HBV) is often acquired perinatally or from child-to-child contact in household settings, and is thus not as reliable a marker for injection drug use as it is in other regions.

Behavioural measures

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

Behavioural surveillance of MSM attempts to determine:

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

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 sex workers
- MSM venues.

When conducting behavioural surveillance of MSM, specific indicators may include:

- percent of MSM reporting the use of a condom the last time they had sex with a male partner (UNGASS)
- percent of MSM who have had anal sex with more than one male partner in the last 12 months (MEASURE)
- percent of male sex workers reporting the use of a condom with their most recent client (UNGASS).

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 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.ungass.org/index.php/ungass/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 key to the spread of HIV among MSM. These guidelines are available online at: <http://www.fhi.org>.
- The HIV/AIDS Survey Indicators Database of MEASURES DHS includes applicable health indicators that are used to evaluate attitudes and behaviour relative to the health risks measured by HIV and STI prevalence surveys. These indicators are available online at: http://www.measuredhs.com/hivdata/ind_tbl.cfm.

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 research 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 inadvertent identification as an MSM
- inadvertent disclosure of HIV status
- negative reaction and backlash in response to publicised results
- physical abuse
- imprisonment.

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

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

Language, social perspective 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 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 them. Explaining these issues to them 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
- limiting access to any identifying information to authorised personnel
- keeping study documents in a locked, limited-access room
- having all staff sign confidentiality forms and undergo training in research ethics.

Summary

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

Biological and sero-surveillance of MSM in Millao, Malanka

Part 1: Collecting information to plan surveillance activities

Millao, a cosmopolitan city with a population of three million, is the capital of Malanka, an island nation in South-East Asia.

Since Millao is the financial and cultural centre of the country, many men are drawn to the city. Although homosexuality is officially prohibited, Millao has an active selection of venues catering to MSM, including saunas and dance clubs.

Annual sentinel surveillance for the past five years has found an increase in the incidence of rectal gonorrhoea among male STI clinic attendees in Millao. The Ministry of Health is concerned that there may be an undetected epidemic of STI and HIV among MSM.

Because homosexuality is illegal in Millao, MSM are often discriminated against and harassed by local police. As a result, MSM mistrust local officials. For this reason, the Ministry of Health has, in the past, had difficulty conducting biological and behavioural surveillance among MSM.

This year, the Ministry of Health has decided to conduct biological and behavioural HIV/STI surveillance of MSM in Millao. As the HIV surveillance officer of Millao, you are tasked with designing and conducting this activity.

1. What information is required for planning the survey?
2. How will your office obtain this information?

Part 2: Building key alliances with community networks involving men who have sex with men

In order to plan for the survey, you will need to 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 Millao 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 in Millao. Information can be obtained from websites, through interviews, through ethnographic mapping and by observation.

3. Describe how you would conduct research as the first part of designing a comprehensive HIV surveillance effort for MSM.
4. 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 influential MSM in Millao, you form partnerships with local NGOs 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 can also work with local law enforcement agencies to ensure that police do not harass MSM who participate.

Through formative research, you find an extensive local MSM scene. After conducting focus-group discussion and in-depth interviews with MSM, you find out that MSM in Millao congregate in a wide range of venues. Sex takes place in some of these venues, which include saunas, gyms, dance clubs and public parks.

5. What sampling scheme is most appropriate?
6. What are the advantages and disadvantages of time-location sampling (TLS)?

Part 4: Collecting biological and behavioural data

You decide to conduct HIV prevalence and risk-behaviour surveys of MSM every other year, using a time-location sampling method. There are many advantages and

disadvantages of TLS. Although TLS requires mapping and time-consuming ethnographic work and may only reach a subset of MSM, it allows for a probability sample of hidden or 'floating' MSM.

7. What biological variables do you include?
8. What behavioural variables do you include?
9. What additional steps are needed to test for HIV?
10. What are some of the special ethical considerations for this surveillance activity?

Part 5: 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.

To acquire this data, you will 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 this issues facing MSM. Additionally, as you will be testing for HIV, you should establish a mechanism in which persons who test positive for HIV are referred to treatment and counselling.

This study produces the following results:

- HIV prevalence was 9%.
- Syphilis (TPHA) prevalence was 14.0%.
- HSV-2 prevalence was 20%.
- Gonorrhoea prevalence was 5%.
- Chlamydia prevalence was 1%.
- 65% 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.

11. Describe how you would use the data collected to develop MSM-focused prevention programmes?

Part 6: Epilogue

Millao has a large population of men who have sex with men, including male sex workers, transgendered individuals, men who have sex with men and identify as homosexual and men who are married and identify as heterosexual. Because homosexuality is prohibited, men who have sex with men in Millao can be fearful of the authorities and often do not seek medical care when needed. MSM in Millao are at high risk of acquiring and transmitting HIV. Some MSM have high partner turnover and low condom use; many do not seek treatment for STIs or other health problems; many are injection drug users and many have been incarcerated. Targeted interventions are needed to promote safe sex practises among MSM in Millao.

Based on these findings, the Ministry of Health directs the HIV programme manager to initiate the following interventions:

1. Engage peer and NGO outreach workers to educate MSM about the need for consistent condom use with non-regular and regular partners.
2. Distribute condoms to MSM through peers, NGO workers and STI clinics in the red light district.
3. Organize education and outreach programmes to encourage MSM to seek treatment for STIs.

Notes

Overview

What this unit is about

This unit describes the background and special considerations associated with studying 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 voluntary migrants, and which terms are used to describe involuntary migrants?
 - a. refugees
 - b. displaced persons
 - c. mobile populations
 - d. none of the above.
2. True or false? Both biological and behavioural surveillance on migrant workers should be conducted regularly every year.

True	False
------	-------
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. List two sub-groups that can be considered mobile populations.
 - a.
 - b.
5. Which type of migration occurs regularly in the South-East Asia region and usually involves young people who move from low-prevalence areas to high-prevalence areas and eventually return home?
 - a. 'circular' or 'oscillating migration'
 - b. gross migration
 - c. step migration.

Introduction

What you will learn

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

- describe the special considerations associated with surveillance in mobile populations
- distinguish between the various types of mobile populations
- describe options for sampling and surveillance methods among mobile populations.

Background

Definitions

This unit focuses 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 who move 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 (includes truckers, miners, sex workers, fishermen, military personnel, etc.)
- involuntary (includes refugees, trafficked sex workers, and internally displaced people).

Please note that although military personnel may be considered mobile persons, the special considerations associated with studying military personnel are discussed in Unit 8.

There are many people who are involuntary migrants, including *refugees* and *internally displaced persons (IDPs)*. By legal definition, refugees are persons 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. This definition only includes persons who have been displaced from their homeland and have sought refuge in a second country. Internally displaced persons are persons who have left their homes due to civil unrest, natural disasters, political and/or religious persecution, but have stayed in their homeland and have not sought sanctuary in another country.

According to the Internal Displacement Monitoring Centre (IDMC) of the Norwegian Refugee Council (NRC) more than two-thirds of Asia's three million internally displaced people are in South Asia. As of 2006, the number of IDPs in Asia varied, including the following examples:

- India: at least 600 000 internally displaced persons (IDPs)
- Bangladesh: 500 000 IDPs

- Nepal: 100 000 - 200 000 IDPs
- Myanmar: 500 000 IDPs
- Indonesia: 150 000 - 250 000 IDPs
- Sri Lanka: 600 000 IDPs.

Types of migration

Although there are many different types of migration, a common mode of migration in South-East Asia is *circular* or *oscillating migration*. This type of migration is characterized 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 are the following:

- married men who relocate from rural to urban areas for seasonal or long-term jobs and 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 persons moving out of their homes to work elsewhere, migrants also include people in the transportation industry, such as truck drivers and merchant seamen, who travel frequently across long distances.

The mobile populations include many groups, such as the following:

- persons (for example, salesmen and short distance truckers) travelling between home and business locations daily or weekly, away from home and family for short durations
- long-distance transportation workers who are away from home for several months, but do not necessarily establish permanent residences
- merchant seamen.

Additionally, civil strife, political tension and natural disasters, to the extent they reduce economic opportunities for young people in their rural homes, often result in migration.

Role of mobile populations in the epidemic

Mobile populations are at high risk for both acquiring and transmitting HIV and STIs. Mobile persons often serve as a bridge between female sex workers and the general population. Additionally, due to migration patterns, mobile populations often bring HIV from high-prevalence areas to low-prevalence areas. Studies in several countries have demonstrated the importance of major transportation corridors in the spread of HIV. 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. From an epidemic-spread perspective, this pattern is most critical to identify when there are sufficient high risk networks at these migrants' point of origin to sustain a local epidemic (for example, if wives are also engaging in selling sex in their home villages/towns while their husbands are away).

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 where much risky behaviour is occurring, 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.

Work-related migration often creates an imbalance in the ratio of women to men which results in the sharing of partners and an increased demand for sex workers. Long-distance truck drivers or persons in other occupations that entail long travel away from home are often the clients of female sex workers more frequently than the general population.

Many forms of sex work are common in border towns and port areas where truckers travel. This sex work is often based in bars, nightclubs and brothels. It is also common for sex workers to have sex with drivers in their trucks as they wait in lines to load or unload cargo or get proper documentation. Sex workers in some countries are also highly mobile.

Sex is not the only common medium of HIV transmission among migrants. Both male and female migrants are often at risk for parental transmission because of injection drug use, traditional medical practices and unsafe therapeutic injections. The trafficking of illegal drugs is also an important driver of the epidemic among migrants.

Prevalence of HIV among mobile populations

Limited data are available in South-East Asia on the prevalence of HIV infection among mobile populations. A 2002 study conducted by Family Health International in the Achham district of Nepal found that international migrants had the highest rate of HIV infection (3.7%), followed by internal (3%) and non-migrant sub-groups (0.7%).¹⁵ According to the sentinel surveillance data conducted by the National AIDS Control Organisation of India, the median HIV prevalence among truck drivers in 2006 was 2.4%.

Examples of mobile populations and migrants

There are many different groups that are mobile or are migrants. The employment-oriented seasonal and short-term migration of Nepalese youth and young adult men to the cities of Nepal, to India, and to other countries is emerging as a major factor in driving the HIV epidemic in Nepal. Young and mobile men, who tend to be away from home for periods ranging from a few months to a few years, are likely to be involved in casual sex with non-regular partners, including sex workers.

In the Indian state of Tamil Nadu, the government, community groups and other development partners confronted the epidemic after studies found that 30% of truck

drivers reported sex with a female sex worker in the preceding 12 months. Just over half had used a condom the last time they had paid for sex. Sex work appears to be a common feature in most of these studies.

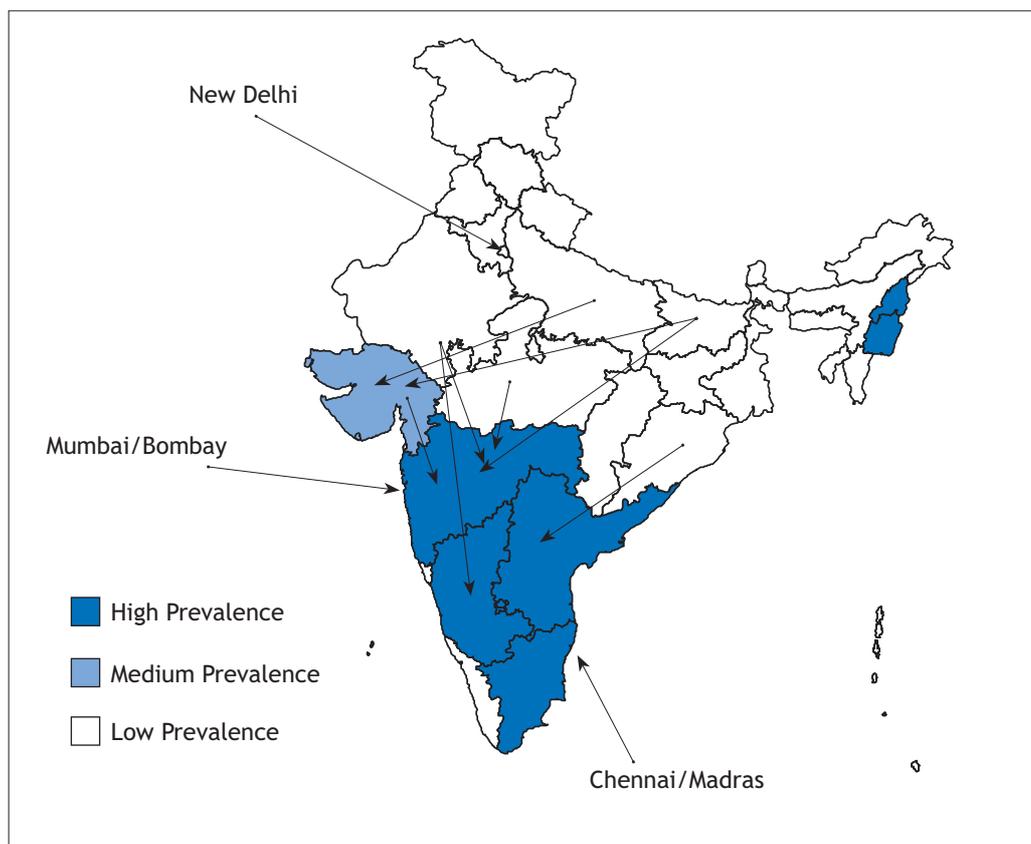
Figure 5.1 shows the migration of Indian population from areas of low prevalence to states where the HIV prevalence is high. In many of the northern states, the HIV prevalence among high risk groups is less than 5%. Numerous migrants from those states moved to areas where HIV prevalence in antenatal clinics is above 1%, constituting a generalized epidemic.

Role of mobile populations in surveillance

There is a large—and increasing—number of migrant workers moving from rural villages to cities, as well as to other countries in the South-East Asia region. However, many countries 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 of the prevalence of and trends in HIV among the mobile populations. This unfortunately has the effect of giving the wrong impression that some countries with large migrant communities and with high HIV prevalence are actually low-prevalence countries.

Figure 5.1

Indian population movement from low to high-prevalence regions



Source: National AIDS Control Organisation (NACO), Government of India (2003).

Conducting Formative Research

Formative research will be necessary to design the survey or study best suited to the group, given the range of possibilities. Formative research will also help to identify the various points of access to the groups and places where surveys and studies could be conducted. Which migrant groups you survey will depend on the specific situation in your country or region.

Listed in Table 5.1 below are recommendations for proposed surveillance methods for mobile populations.

Table 5.1

Recommendations for proposed surveillance methods for mobile populations

1. Conduct formative research to map mobile populations and to categorize the sub-populations in the region by patterns of movement and probability of transmission.
2. Prioritize the populations and geographic areas for conducting surveillance, based on potential for epidemic impact.
3. Develop definitions for mobile populations (truck drivers, miners, construction workers, sailors, fishermen and others) in regions prioritized for surveillance.
4. Build key alliances with community networks involved with mobile populations (for instance, employers and border patrol).
5. Gain collaboration of existing prevention programmes, if they exist.
6. Design surveys or studies.
7. Collect HIV sero-prevalence data, behavioural data and STI data.
8. Analyse and disseminate data.

Pre-surveillance assessment

The first step in planning HIV surveillance in mobile populations is to gain an understanding of the population or populations in your area through formative research. Conducting a pre-surveillance assessment will help you determine the diversity of mobile sub-populations, identify key indicators to measure and determine the geographic areas and venues where mobile persons may be found in high numbers.

A critical component of formative research is gaining an understanding of the patterns of movement and the volume of people travelling. This will help you determine epidemic impact and subsequent prioritization of surveillance groups/areas.

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 these persons is challenging. You can locate and access mobile persons by:

- visiting the venues where they congregate/work

- interviewing and working with persons who have regular contact with mobile persons
- collaborating with organisations that provide service(s) to these groups.

HIV prevalence in mobile populations may be highest in well-travelled border towns and ports. These towns and ports, therefore, may be appropriate and convenient sites for surveillance. Possible locations where mobile persons may be found in high numbers include:

- truck stops and roadside hotels
- brothels in border towns or near construction, mining and/or fishing areas
- highway STI clinics
- health clinics operated by construction or mining companies.

A pre-step for deciding on a sampling method is to decide whether to sample at the point of origin or the point of destination for the migrants/mobile populations. This will depend on the aggregation of people at one end or the other, as well as whether the epidemic impact is being assessed for a particular geographic region, that is the point of origin or the point of destination.

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:

- border patrol, immigration police, customs agents, police and harbour masters
- employers
- employment agencies
- bar tenders
- union officials
- operators of truck stops, fish markets or other places where these groups may congregate
- 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 the managers 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.

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, made up of various leaders, can promote consultation, input and advice on the design and implementation of surveillance. Below is a list of potential members for a community advisory board for HIV surveillance among migrant workers at a large manufacturing plant. The actual composition of a board 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
- occupational health nurses
- occupational health academic faculty.

Conduct ethnographic mapping

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

- the places where mobile populations may be found
- time period
- types of mobile populations and sub-populations in your area.

This information can inform you as to where and when mobile persons can be found and recruited for surveillance activities, and what sub-populations can be found in different areas.

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 research. Table 5.2 lists some examples of what migrant groups might be useful for particular communities and how to access the populations.

Table 5.2

Choosing a migrant population to survey based on community characteristics: some examples

Sample community characteristics	Migrant population to survey	How to access the population
Town with large worksites, such as construction sites or manufacturing plants	Migrant workers in construction site or manufacturing plant	Companies can often provide access to employees through their occupational medicine departments
Port cities	Long-distance truck drivers	Surveys of truckers as they wait in line
	Merchant seamen	Union records
Rural areas that border the sea or a large inland lake	Fishermen	Systematic survey of boats as they return to port

The examples in the table above deal with men who have migrated away from their homes for work and are at risk of acquiring HIV, typically from sex workers. On the other hand, sex workers are often economic migrants as well, who will leave poorer areas to work in places with greater affluence and more ready cash. Sex workers will often cross borders or even continents.

Examine STI clinics

You may also find mobile persons in large numbers at STI clinics.

- Some STI clinics are located along major trucking routes.
- Other STI clinics do not specifically cater to mobile persons, but do include a high number among their patients.

If these STI clinic clients are to be considered for surveillance of mobile populations, occupational information must be systematically and routinely recorded.

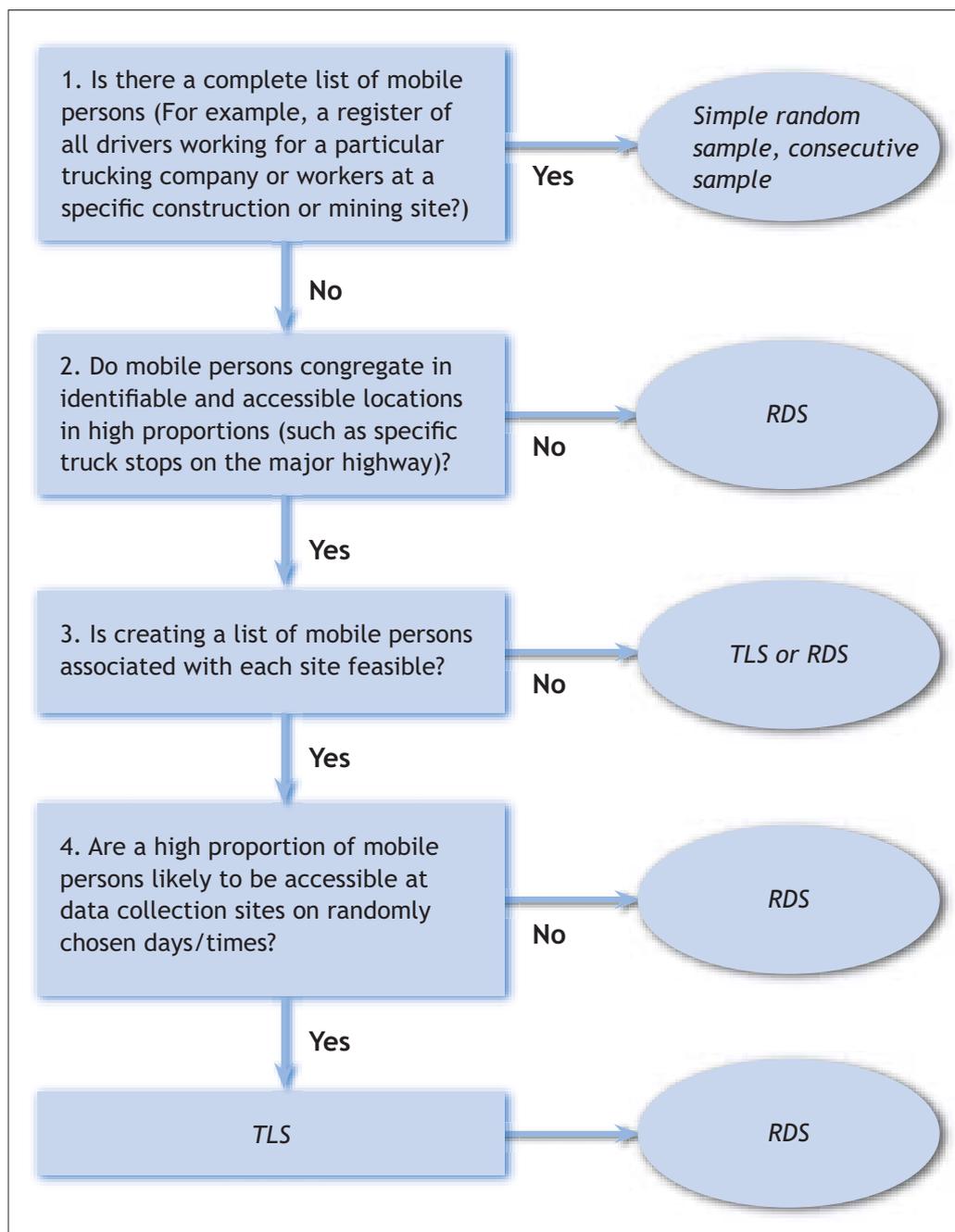
Select a Sampling Method

Sampling methods

Methods for surveillance in migrants are similar to those used in other high risk populations in this module. These methods include:

- HIV prevalence studies
- surveillance for STIs
- behavioural surveys to identify social, behavioural and biomedical risk factors associated with HIV transmission.

Figure 5.2
Selecting sampling methods for mobile populations



There is no particular ‘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 where the best places to find them are.

The following table summarizes some of the possible methods of surveying various migrant groups.

Table 5.3

Examples of possible methods of surveying various migrant groups.

Migrant group	Possible survey methods
Truck drivers/assistants.	<ul style="list-style-type: none"> • Simple random sampling, cluster sampling or systematic sampling, if trucking companies provide lists of their employees.
Miners, factory and construction workers.	<ul style="list-style-type: none"> • 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 (for example, truck drivers and fishermen).	<ul style="list-style-type: none"> • Time-location sampling (for example, truck drivers stopping for dinner along a specific highway).
Merchant sailors.	<ul style="list-style-type: none"> • Simple random sampling (for example, if a list of seamen exists at a union hall).

An example, sampling migrant workers

An important element of these studies relates to 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 are often introduced to new patterns and norms of sexual behaviour and use of the sex facilities 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 numbers of persons working at the sites is small (for example, fishing boats or 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

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 tests, refer to Appendix E: Laboratory tests available for measuring biological outcomes among high risk groups.

- Syphilis testing is often the most efficient biological indicator because the standard tests can be done with the same serological specimen as HIV testing. The test is relatively inexpensive and widely available.
- Accurate tests for gonorrhoea and chlamydia are expensive and usually require a urine specimen.
- HSV-2 testing is a marker for lifetime sexual risk. 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 research, 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.

Several international organisations have sought to standardize a set of “core” or basic indicators of HIV risk among mobile populations (truck drivers, in particular). These include:

- correct identification of ways of preventing the sexual transmission of HIV and rejection of major misconceptions about HIV transmission (UNGASS)
- condom use at last sex with a non-marital, non-cohabiting partner (MEASURE)
- correct identification of the use of condoms as means of protection against HIV infection (MEASURE)
- sex with a sex worker in the last 12 months (MEASURE)
- condom use at last sex with a sex worker, of those who report having had sex with a sex worker in the last 12 months (MEASURE)
- reported symptoms of STIs in the last 12 months and seeking care at a service provider with personnel trained in STI care (MEASURE).

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:

- knowledge of HIV and STIs
- number of sex partners, types
- 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/regular partnership status
- basic demographic characteristics
- the length of time spent away from home/regular sex partners
- where they travel and how often
- whether they cluster in communities that mimic their home/living conditions, types of social support.

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 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.ungass.org/index.php/ungass/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 key to the spread of HIV among FSWs. These guidelines are available online at: <http://www.fhi.org>.
- The HIV/AIDS Survey Indicators Database of MEASURE DHS includes applicable health indicators that are used to evaluate attitudes and behaviour relative to the health risks measured by HIV and STI prevalence surveys. These indicators are available online at: http://www.measuredhs.com/hivdata/ind_tbl.cfm

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 research 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 injection drug user could result in firing or deportation.

Also, you should consider your ability to obtain true informed consent when mobile persons may be coerced to participate or not participate by their employer.

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 even 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 minimize them. 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 bridge between female sex workers 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 you can find them.

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 in your country.
2. Does your country conduct behavioural and/or sero-surveillance of mobile populations (such as, truckers)?
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?

Biological and Behavioural Surveillance Among Truck Drivers in Nodesh

Part 1: Collecting information to plan surveillance activities

Bangalay, with a total population of 15 million, is the capital of the South-East Asian country of Nodesh. Jawara, the northernmost province, borders Serosia and is thought to be a common drug trafficking area. Bantak, to the south, is the country's major deep-water port and a docking place for merchant marines, cruise ships and local fishing vessels.

Sero-prevalence surveys conducted in Bangalay have consistently found a low HIV prevalence. However, similar surveys conducted over the past five years have found that prevalence levels of HIV among injection drug users in Jawara and STIs among female sex workers in Bantak are rising at an alarming rate.

The Nodeshi 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 Nodesh, and holds a meeting with her HIV surveillance team to plan for the survey.

1. What information is required for planning the survey?
2. How might the HIV surveillance team obtain this information?

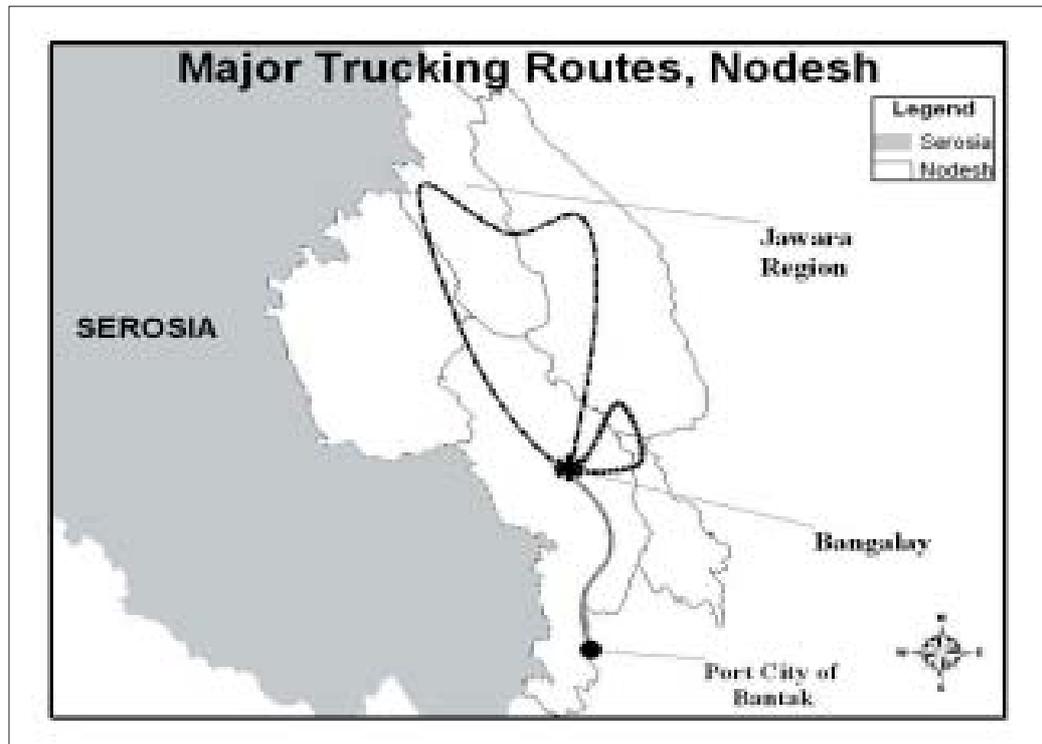
Part 2: Choosing a sampling approach

To obtain background information for designing a behavioural survey, the HIV surveillance team reviews several documents, including published literature, reports of NGOs, reports from trucking companies and clinic records from roadside STI clinics. Interviews of key informants are conducted using open-ended questions. Several key informants are also contacted, including the owners and managers of several trucking companies, truck drivers and helpers, the Ministry of Transport, representatives of the trucking union and staff of roadside STI clinics.

Through discussions with key informants and a review of the available literature, the surveillance team discovers that there are 140 trucking companies in Nodesh, employing approximately 20,000 truck drivers. All trucking companies have offices in Bangalay, where truck drivers must report on a frequent basis to receive their trip assignments.

The HIV surveillance team also discovers 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 Bangalay and the northern district of Jawara, which borders Serosia
- a medium-distance route between Bangalay and the deep-water port of Bantak in the south of the country
- local routes between Bangalay and the surrounding areas.



The HIV surveillance team conducts a census of the trucking companies in Nodesh 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 learns 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.

3. 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 during the preceding three months) with sex workers 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.

4. 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 Nodesh. Because the team was 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 decides to employ *probability-proportional-to-size* (or 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 stratifies 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 determines 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 employs only 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 selects ten truck drivers from each selected trucking company. A total of 400 truckers are successfully recruited.

5. Describe how you would randomly sample 10 truck drivers from each company.
6. What behavioural variables should be collected?
7. What biological variables should be collected?

Part 4: Collecting survey information

Between January and April 2006, the team of field workers visit the selected trucking company's office at the Bangalay truck stand to recruit subjects. The Bangalay truck stand is selected as the best site for recruitment, as all companies have offices at the Bangalay truck stand and all drivers must visit the office to receive their trip assignments. Assuring the participants that confidentiality will be maintained, the field workers explain the purpose of the study to the drivers and obtain their 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
- Herpes simplex virus-2 (HSV-2) - a marker of lifetime sexual risk, for example, multiple sex partners
- syphilis
- gonorrhoea
- Hepatitis C - a marker for injection drug use.

Interviewers administer semi-structured questionnaires to the truck drivers to assess their sexual and injecting risk behaviours. Variables collected included:

- socio-demographic information (age, marital status, employment history, etc.)
- alcohol and drug use
- types of female sex partners in the past year
- MSM activity
- condom use
- history of diagnosis with STI, current symptoms of STI
- injection drug-use behaviours (types of drugs injected, frequency, needle-sharing and use of sterile equipment).

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)
- Hepatitis C prevalence: 12% (48/400).

The survey produces the following behavioural results:

Risky sexual behaviour is common, with few truckers reporting consistent condom use, despite having high numbers of sexual partners. Both premarital and extramarital sex are common. Both married and non-married truckers report multiple sex partners, often with FSWs.

Nearly 10% report male-male sex ever and fifteen percent 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 having had 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 FSW 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 FSW in port of Bantak
- 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 (many with multiple wives and/or regular sex partners in different locations)
- little contact with sex workers
- high prevalence of untreated gonorrhoea and syphilis
- no reported injection drug use
- no HIV cases.

8. 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 truck 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 Nodesh, targeting truck drivers with behaviour-change interventions could be an important means of avoiding an HIV epidemic.

Based on these findings, the Nodesh Minister of Health directs the HIV programme manager to implement the following measures:

- a. 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 sex workers and regular partners.
- b. To establish harm-reduction programmes for IDUs and provide sterile injecting equipment to IDU truck drivers at the large truck stops along the Bangalay-Jawara trucking routes.
- c. To establish workplace-based STI screening and HIV education for local-route drivers.
- d. To improve the service provided at roadside STI clinics by ensuring drug supply and training staff on proper STI management.

Notes

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 of out-of-school youth for surveillance
- describe the special ethical considerations associated with conducting HIV surveillance activities in 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 unaffordable school fees (such as tuition, books, uniforms, etc.), 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 facilities—lack of schools or shortage of trained teachers may narrow educational opportunities.
- Poor infrastructure—poor roads and/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.

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 members in the family 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

In the South-East Asia Region, *out-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 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 prostitution, live and work on the streets, or be unemployed.

Sub-populations of out-of-school youth

OSY often live under challenging conditions and are marginalized from mainstream services and society. In South-East Asia, OSY at risk of HIV infection can be grouped into one or more of the sub-populations discussed in Table 6.1.

Table 6.1

Sub-populations of out-of-school youth

Group	Definition
Street children	<ul style="list-style-type: none"> Includes orphaned, homeless, runaway or neglected children who live chiefly in the streets without adequate protection, supervision or direction from responsible adults.
Child labourers	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Includes any person under the age of 18 involved in the sex industry. Adolescent sex workers often do not have the ability to resist sexual aggression or demand that their clients use condoms.
Married adolescents	<ul style="list-style-type: none"> Includes girls who are married before the age of 18 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.

In the Asia-Pacific region, it is estimated that over two million young people aged 15-24 years live with HIV, with widening epidemics in many countries in the region.¹⁶ Young people are often more likely than their elders to engage in high risk behaviour, making them more susceptible to the risk of 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.

The types of risks and social factors underlying HIV infection among OSY categories differ, as outlined in Table 6.2 below.

Table 6.2

The vulnerability of OSY to HIV

Group	Risk and social factors
Street children	<ul style="list-style-type: none"> • are often sexually active • may have multiple sex partners, including female sex workers • may provide sex in exchange for money • may be sexually abused • may inject drugs • have less access to prevention information through schools • may be involved in gangs and/or drug trafficking • generally don't receive appropriate medical care.
Child labourers	<ul style="list-style-type: none"> • have less access to prevention information through schools • may be sexually abused in the workplace • may be involved in sex work.
Adolescent sex workers	<ul style="list-style-type: none"> • may not have the right or ability to resist sexual aggression • 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	<ul style="list-style-type: none"> • may not be able to control a husband's infidelity or resist sexual abuse • younger women are more susceptible to contracting STIs due to immature genital tracts • have less access to prevention information through schools.

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 out-of-school youth varies by country and region, as illustrated by the following data:

- In Nepal, 11% of the reported HIV cases are among youth younger than 19 years of age.¹⁷
- A study among FSWs in India indicate that the highest HIV sero-prevalence was among the younger sex workers (<20 years of age), with 12% testing HIV-positive.¹⁸
- In Bangkok, Thailand, the prevalence of HIV among MSM aged 22 years or younger has risen from 13% in 2003 to 22% in 2005.¹⁹
- In Indonesia, the prevalence levels of STIs and HIV/AIDS infection among street youth are unknown, but it is estimated that in Jakarta, one in every seven street children has a history of STIs.
- In Myanmar, the prevalence of HIV among young people aged 15-24 was found to be 2.2% in 2005, compared to a national adult HIV prevalence of 1.3%.²⁰

Role of OSY in surveillance

In South-East Asia, people between the ages of 10 and 24 are one of the fastest-growing groups of new HIV infections. 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 are specifically targeted toward out-of-school youth, including:

- mass media campaigns
- promotion of youth-friendly health services
- condom use promotion and life skills education
- voluntary counselling, testing and 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 that will help monitor any specific behaviour changes observed in these groups.

Overlap with other populations

In many areas, young people constitute a significant percentage of FSWs, IDUs and MSM. For example:

- In Cambodia, Laos, Myanmar, and Vietnam, between 60% and 70% of sex workers are younger than 25 years of age.
- In Central Asia, up to 25% of IDUs are estimated to be less than 20 years old.
- In Indonesia, 70% of injecting drug users are younger than 25 years.
- Many clients of sex workers are also young. Data from behavioural surveys conducted in India and Nepal found that between 17% and 70% of the clients of sex workers are young, with the majority aged 20-24 years.
- In Myanmar, sentinel surveillance conducted between 1989 and 2003 found that 41% of FSWs age 15-24 were HIV positive.²¹

Conducting Formative Research

The first step in planning HIV surveillance in OSY is to gain a better understanding of the sub-populations of OSY in your area.

Pre-surveillance assessment

Pre-surveillance 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 high numbers. The aims of the pre-surveillance 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 to one another within

a given country, or even within a given city. Identifying points of access and forming alliances with organizations 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. 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 facilitate locating and accessing OSY, consider:

- identifying and interviewing persons known to have regular contact with OSY
- visiting areas where they are known to congregate
- collaborating with organisations that provide education, food and/or 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 sex workers, 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 are:

- influential current and former sex workers, 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 conducting youth-targeted HIV prevention and care programmes
- national and international advocacy groups dealing with OSY issues.

These people and organisations can also assist later in implementing surveillance activities. For example, former adolescent sex workers 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 representing OSY or a particular sub-group in your area. This sampling frame provides the basis for some probability-based sampling methods.

The 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:

- 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. However, depending on each country or region, OSY may be registered as sex workers 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.

Select a Sampling Method

Hard-to-reach populations, such as out-of-school youth, 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 (since 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 out-of-school youth are difficult to access. Many OSY are married and/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. Conducting a pre-surveillance assessment will help you identify the sub-groups of OSY in your area and will provide information on how they can best be accessed and sampled.

Probability sampling techniques like 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 pre-surveillance 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 within their own peer group.

Food items are often used as incentives when conducting RDS among children and adolescents. Organizations 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.

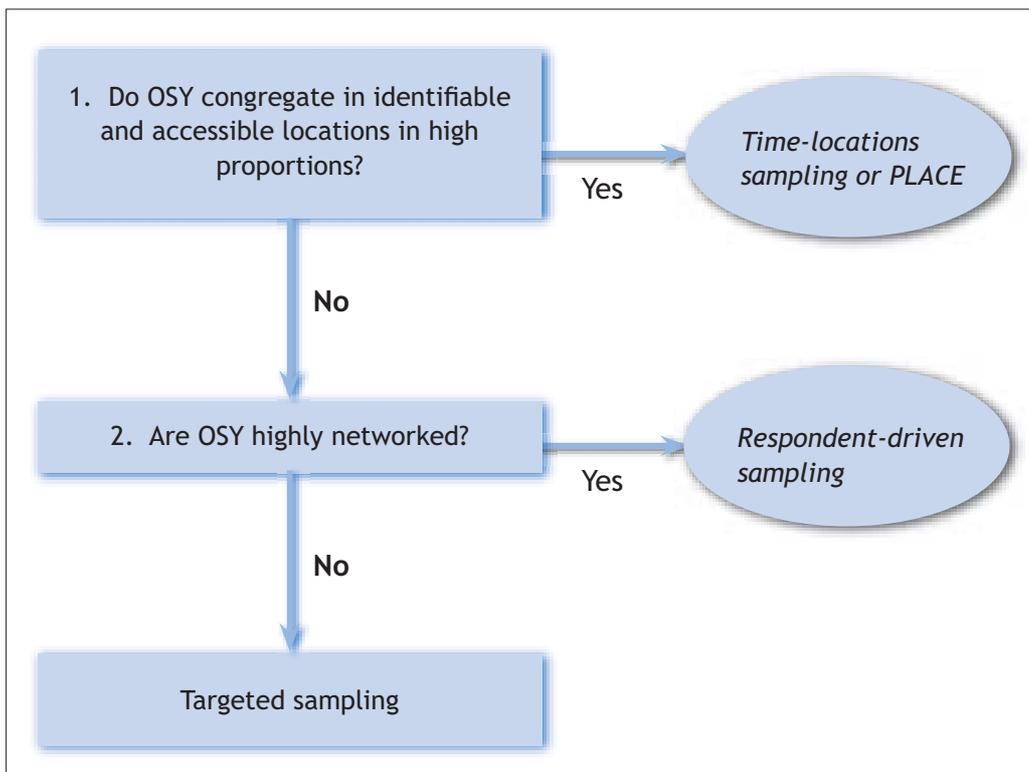
Priorities for local AIDS control efforts

The PLACE (Priorities for Local AIDS Control Efforts) protocol is a new rapid assessment tool used to identify high transmission areas that formalize the collection of information in high-transmission areas. PLACE use key informants to identify locations where people meet new sex partners, then interviews people at the site to characterize the site in each area and map sites. PLACE also interviews individuals socialising at the site to describe the characteristics of the people at the site.

Figure 6.1 will help you select an appropriate method for sampling out-of-school youth in your area.

Figure 6.1

Selecting sampling methods for out-of-school youth



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

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 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 intravenous drug users, 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, FSWs, MSM, or IDU), consider using indicators that assess high risk behaviours among these groups.

The indicators that may be appropriate in situations where there is suspected overlap between out-of-school youth and other high risk groups are presented in Table 6.3 on the next page.

Table 6.3

Additional indicators to include when there is suspected overlap between OSY and other high risk groups

Group	Indicators
Female sex workers (FSWs)	<ul style="list-style-type: none"> • venue of sex work • number of paying customers • condom use with paying customers
Injection drug users (IDUs)	<ul style="list-style-type: none"> • 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)	<ul style="list-style-type: none"> • number of male sex partners • frequency of <i>unprotected anal intercourse (UAI)</i> • frequency of <i>unprotected receptive anal intercourse (URAI)</i>

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 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.ungass.org/index.php/ungass/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 key to the spread of HIV among IDUs. These guidelines are available online at: <http://www.fhi.org>.
- The HIV/AIDS Survey Indicators Database of MEASURES DHS includes applicable health indicators that are used to evaluate attitudes and behaviour relative to the health risks measured by HIV and STI prevalence surveys. These indicators are available online at: http://www.measuredhs.com/hivdata/ind_tbl.cfm.

Special Ethical Considerations

Because OSY are young and often involved in activities such as prostitution or child labour, they are often stigmatized 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, sex worker or undocumented labourer)
- inadvertent disclosure of HIV status
- negative reaction and backlash in response to publicized results.

It may also be difficult to obtain true informed consent, due to the lower education and literacy levels common among OSY.

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.

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 minimize them. Explaining these issues to them is part of the *informed consent* process.

Steps you can take to minimize 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 authorized 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 minimize 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 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

In the South-East Asia Region, *out-of-school youth* include diverse sub-populations, including street children, child labourers, adolescent sex workers, married adolescents and child soldiers. As people between the ages of 15 and 24 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 organization and accessibility of out-of-school youth 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 in your surveillance activities, you should seek special guidance on research with children.

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 out-of-school youth?
2. In your country, who are the gatekeepers of this population?
3. In your country, what methods have been used to sample out-of-school youth?
4. In your country, what behavioural and biological measures have been used when conducting surveillance of out-of-school youth?
5. In the past five years, has the prevalence of HIV among out-of-school youth increased, decreased or remained about the same?

Apply what you have learned/case study

Conducting behavioural surveillance among street youth In Indam, Serosia

Part 1: Collecting information to plan surveillance activities

Indam City, with a total population of 5 million, is the economic and administrative capital of Serosia, a large South-East Asian country.

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 Serosian 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 Indam Metropolitan area is alarmed by recent NGO reports that an increasing number of street youth, some as young as 15, 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 Indam Commissioner of Public Health directs the HIV Programme Manager to undertake a survey of street youth in Indam to determine the sexual and injecting behaviours of these youth 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 Indam 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 needs 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 reviews 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 collects 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 realizes 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 decides that in order to access street youth, they must enlist support of gatekeepers whom the street youth know and trust.

3. Who are important gatekeepers that can help the HIV team gain access to the street youth in Indam City?
4. 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 learns that many of the street youth are organized 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 meets with 'senior' street youth who have influence among other street youth.

The HIV team also meets with NGO managers and the police in the area.

A briefing meeting is organized, 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 is now set to move to the next step.

5. What sampling methods are appropriate for sampling street youth in Indam City?
6. What are the advantages and disadvantages of each approach?
7. How would the HIV team construct their sampling frame?
8. What kinds of incentives should the HIV team offer to the street youth who participate in the survey?

Part 4: Collecting behavioural data

The HIV team considers their sampling options and determines that they could:

- 1) conduct targeted sampling
- 2) conduct time-location sampling at the locations where street youth congregate
- 3) use snowball sampling
- 4) conduct respondent-driven sampling.

The team weighs the pros and cons of each approach. The team considers 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 time-location sampling or respondent-driven sampling, 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 time-location sampling as a probability sampling method, the team decides to conduct TLS to obtain a representative sample of street youth in Indam City.

The HIV team constructs 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 hawk goods, and parks where street youth congregate. The team then visits these venues and count the number of street youth present at the venues at specific times. The team statistician determined that the HIV team needs 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.

9. 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 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 ever experienced any kind of sexual abuse in streets, if experienced any kind of sexual abuse in 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 of and exposure to HIV prevention interventions, including the prevention campaign by the national mass media, 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 utilized 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 Indam City 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.

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 ($p < 0.05$).
- 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 (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 ($p < 0.01$)

- Median age of sexual debut was 15 for boys and 13 for girls
- Females reported more sexual partners in 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 by boys (85%) and girls (79%).
- Girls were less likely to report having used marijuana, inhalants and/or methamphetamines in the last year ($p < 0.05$).
- Injection drug use was reported by only two participants (1.2%), both 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.
- 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 utilized these services.
- Fear of being arrested or “sent home” was the most commonly cited reason why street youth did not utilize public health services.

10. Based on the community survey, what are the main factors that put street youth at risk of transmitting and acquiring HIV?

11. 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, had been raped or abused; 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 utilize 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 Indam.

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

1. design interventions specifically targeted at street youths
2. engage peers and NGO outreach workers to educate street youth about HIV/STI transmission and prevention
3. disseminate “best practices” to researchers and practitioners that have worked with street youth across different cities
4. 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

Overview

What this unit is about

This unit describes the background and special ethical considerations associated with conducting HIV surveillance among prisoner populations. 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 injection 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.
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. However, 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 truly 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:

- police stations and jails
- centres for pre-trial and convicted prisoners
- centres for juvenile offenders
- centres for illegal immigrants and/or asylum seekers
- penal colonies
- mandatory re-education and rehabilitation centres (such as, those for drug users and sex workers).

Role of prisoners in the HIV epidemic

There are multiple and powerful factors contributing to the high prevalence of HIV in prisons. These include:

- the high concentration of arrested *injection drug users* (IDUs) and *female sex workers* (FSWs)
- consensual and non-consensual male-to-male sex, especially during long periods of incarceration
- syringe sharing with multiple injectors
- tattooing with unsafe needles (theoretically, although clearly a risk for HBV and HCV).

Furthermore, HIV prevention measures, such as the provision of condoms, are uncommon in prisons. Additionally, although injectable drugs, such as heroin, are available in some facilities (usually illegally), access to sterile injection equipment is limited.

Female prisoners are often incarcerated for sex work. For this reason, female prisoners often have a higher prevalence of HIV than 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

HIV *sero-prevalence* levels have reached alarming levels in many prison populations in Asia and elsewhere in the world. The high HIV *prevalence* levels among prisoners are the result of both the high rates of HIV infection before persons enter prison and of 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.

HIV transmission in prisons has been reported in many countries all over the world. However, 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.

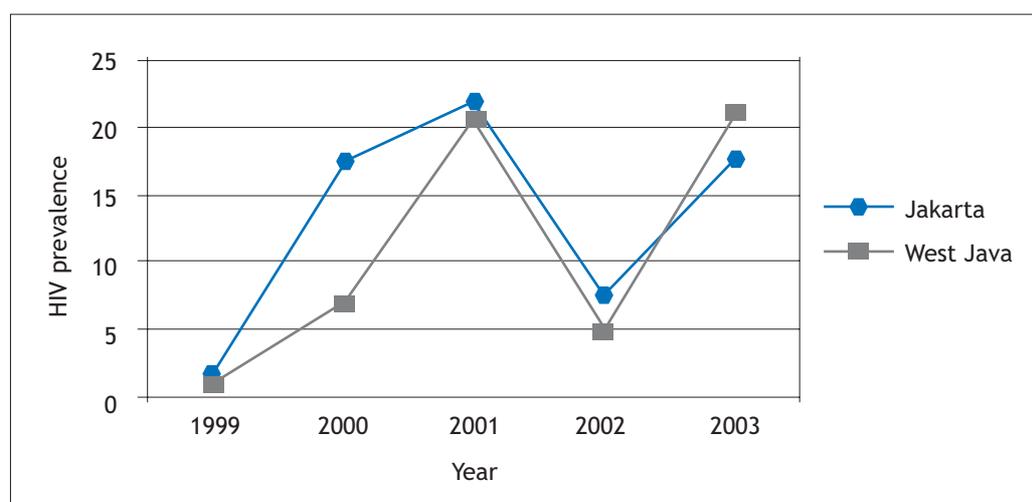
In South-East Asia, the prevalence of HIV infection among prisoners varies by country and region. Consider the following examples:

- the HIV prevalence among prisoners in Indonesia is between 8.6% and 15.4% (2002)
- in 2003, HIV prevalence among prisoners in Jakarta, Indonesia was 17.65%²²
- in India, only one national study of HIV prevalence in prisons has been conducted, finding that 1.7% of all prisoners and 9.5% of female prisoners were HIV-infected
- in 2003, in Amristar Central Jail in India, 1.8% of male prisoners were found to be HIV-infected
- a 2001-2002 study conducted among a cross-section of prisoners in Bangkok, Thailand found an HIV prevalence of 25.4%²³
- in Thailand, India and Indonesia, the HIV prevalence in prisons is between two and 15 times greater than in the general population.

Figure 7.1 shows the prevalence of HIV among prisoners in Jakarta and West Java, Indonesia between 1999 and 2003.

Figure 7.1

HIV prevalence in prisons in DKI Jakarta and West Java, Indonesia, 1999-2003



Source: Ministry of Law and Human Right of the Republic of Indonesia (2005). National Strategy Prevention and Control HIV/AIDS and Drugs Abuse, Indonesian Correction and Detention: 2005-2009. Jakarta, Directorate General Correction, 2005.

As shown in the figure above, the prevalence of HIV among prisoners in Jakarta and West Java, Indonesia has fluctuated in recent years.

Bridges and overlap with other populations

Prisoners overlap with other high risk groups, including IDUs and FSWs. Due to the often-illegal nature of sex work and injecting drug, sex workers 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.

Conducting Formative Research

The first step in planning HIV surveillance among prisoners is to gain an understanding of the population. You will need to gain access to information on the prison system and obtaining authority or permission to conduct surveillance activities in prisons.

Pre-surveillance assessment

As access to prisoners is regulated, you must obtain permission from governmental authorities and/or prison administrators before conducting any surveillance activities.

Building key 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. Prison wardens are important *gatekeepers* who can provide access to prisoners.

Conducting a *pre-surveillance assessment* will help you identify key indicators to measure, the diversity of the sub-populations of prisoners and the infrastructure and procedures of prisons for surveillance purposes.

A pre-surveillance assessment will help you answer the following questions.

- What are the different types of facilities for incarceration in your country (for example, in 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 feasible and ethical?
- Are surveys of prisoners at the time of or immediately following release feasible?
- What are the relationships between the locations of prisons and the geographic areas from which prisoners originate?

Other organizations or individuals may also be helpful, such as:

- correctional officers
- human rights organisations

- prisoner rights organizations
- health or social services programmes for prisoners (if they exist).

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 the norm, 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 a combined biological and behavioural survey on a consecutive or systematic sample of prisoners after their intake or at an initial health assessment. As with all surveillance activities, to be effective, surveillance must be regular and ongoing.

Sampling methods well-suited for use among prisoners include:

- *cluster sampling*
- *stratified random sampling*
- *systematic random sampling.*

Further information on these sampling methods can be found in Module 5: Surveillance of High risk Behaviours.

Measures

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 specifically collect behavioural and biological information on HIV, STI and risk behaviours should be done with informed consent. The focus of the behavioural questions may vary, based on the gender of the prisoner population, as summarized in Table 7.1.

Table 7.1

Focus of behavioural surveillance, by prisoner gender

Prisoner gender	Focus of surveillance
Male	<ul style="list-style-type: none"> • injection drug use before and during incarceration • male-to-male sex in prison • heterosexual sex before incarceration
Female	<ul style="list-style-type: none"> • injection drug use before and during incarceration • heterosexual sex before and during incarceration

Biological measures

Measuring HIV sero-prevalence among prisoners is an integral component of surveillance. The high sexual risk among prisoners 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).

Because prisoners may have injected drugs prior to or during their incarceration, laboratory tests for hepatitis C virus (HCV) may be a useful biological measure.

Possible biological measures to include when conducting surveillance among prisoners are presented in Table 7.2.

Table 7.2

Possible biological measures

Biological measure	Notes
Syphilis	Syphilis testing is often the most convenient and efficient biological indicator because the standard tests can be done with the same serological specimen as 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 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, 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 sex workers and injection drug users 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 sex workers and injection drug users are discussed in Unit 2: Sex Workers and Unit 3: Injection 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 (UNGASS)
- correctly identifying ways of preventing the sexual transmission of HIV and rejecting major misconceptions about HIV (UNGASS)

- correctly identifying condom use as means of protection against HIV infection (MEASURE)
- having had sex with a non-marital, non-cohabiting partner in the last 12 months, of all respondents reporting sexual activity in the last 12 months
- having had sex with a sex worker in the last 12 months (MEASURE)
- engaging in commercial sex work in the past 12 months
- engaging in anal sex with more than one male partner in the last 12 months, of all men surveyed who have sex with a male partner
- engaging in injection drug use in the past 12 months
- sharing needles, syringes or other injecting equipment the last time they injected drugs.

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:

- reason for incarceration
- drug use (injection and non-injection)
- marital status
- occupation before incarceration
- term of sentence (years or months)
- history of attending 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 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.ungass.org/index.php/ungass/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 key to the spread of HIV among FSWs. These guidelines are available online at: <http://www.fhi.org>.
- 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 online at: http://www.measuredhs.com/hivdata/ind_tbl.cfm.

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 research* 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 staffs 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 of prisoners and periodic testing of prisoners and prison staff. This testing is done for clinical purposes in order to identify and treat individuals with latent and active TB and to control TB transmission in prisons. However, results from these surveys 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 that:

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 recognized. 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 and 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 require the input of a prisoner advocate.

Informed consent

When conducting HIV testing among prisoners, you must determine whether the testing is being done for clinical reasons or for surveillance reasons. Mandatory testing of all entering prisoners is performed for clinical reasons. Local laws and regulations cover how this type of testing is to be done. 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 testing usually require informed consent.

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 minimize these threats. Explaining these issues to them is part of the *informed consent* process.

Steps you can take to minimize 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 authorized study personnel only
- keeping study documents in a locked, limited-access room
- having all staff sign confidentiality forms and undergo training in research ethics.

Although it is uncommon in South-East Asia, some correctional facilities isolate HIV-infected prisoners from the general prison populations. In settings where HIV-infected prisoners are kept in separate facilities or areas than 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 evaluated and monitored by institutional review boards (IRBs).

When confidentiality cannot be guaranteed and the potential harm of being identified as HIV-infected is severe, *unlinked anonymous testing* (UAT) may be a more desirable option. By design, UAT precludes the disclosure of participants' names or other identifying information. Module 3: HIV Sero-Surveillance covers the methods of UAT in detail.

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, high numbers of these groups may be present in prisons.

Prisoners are considered a vulnerable 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.

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

Biological and behavioural surveillance of prisoners at Millao Central Prison, Malanka

Part 1: Mandatory HIV testing

Millao, a city with a total population of 12 million, is the capital of Malanka, an island nation in South-East 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 Millao. 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, decides to conduct a sero-prevalence assessment of prisoners at Millao Central Prison. Millao Central Prison is the largest adult male correctional facility in Malanka and houses prisoners from all regions of Malanka. 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, hepatitis C and drug testing of all prisoners upon arrival. A routine physical test is performed and blood and urine samples are collected from all newly arriving prisoners. Blood samples are tested for HIV, hepatitis C and syphilis, and urine samples are tested for chlamydia, opiates and methamphetamines.

Because all new prisoners are screened for HIV, STIs and hepatitis C at intake, the HIV surveillance team decides to analyse data from all prisoners arriving at the prison between January and June 2006.

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 to syphilis
- 189 (27%) are reactive to HSV-2
- 84 (12%) are reactive to hepatitis C
- 385 (55%) test positive for opiates
- 70 (10%) test positive for methamphetamines.

Biological data suggest that persons entering prison were engaged in risky sexual and injecting behaviours prior to their incarceration. To determine whether this is true, the HIV surveillance team decides 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 Millao 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 decides 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 similarly collected. In addition, 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 who arrived at Millao Central Prison between January and April 2006 (35 of whom tested positive for HIV) 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 administers 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.

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, etc) in the month prior to their incarceration.
- Most respondents (82%) reported having visited female sex workers 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 decides to assess the incidence of HIV inside Millao Central Prison.

4. Describe how the HIV surveillance team could measure HIV incidence among Millao Central Prison inmates.

5. 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 Millao Central Prison and the behaviours related to infection, the HIV surveillance team follows 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 report sharing needles and other injection equipment.
- 28% (5/18) of the men who inject heroin in prison are also engaged in unprotected male-male sex while in prison.

Of the 500 HIV-uninfected prisoners:

- 15% (75/500) inject heroin while in prison, all of whom 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 drug injecting (HIV incidence among those reporting male-male sex but no drug injection 8% per year).

The HIV surveillance team concludes that many prisoners who are uninfected when they enter Millao 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.

6. 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.

Notes

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 HIV 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

For the purpose of this unit, *uniformed personnel* 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 of contracting HIV and AIDS. In many countries, HIV *prevalence* is much higher among uniformed personnel than it is in the general populations.

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
- high prevalence of STIs.

Furthermore, deployment to conflict areas increases their chances of acquiring HIV.

This is because of:

- 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

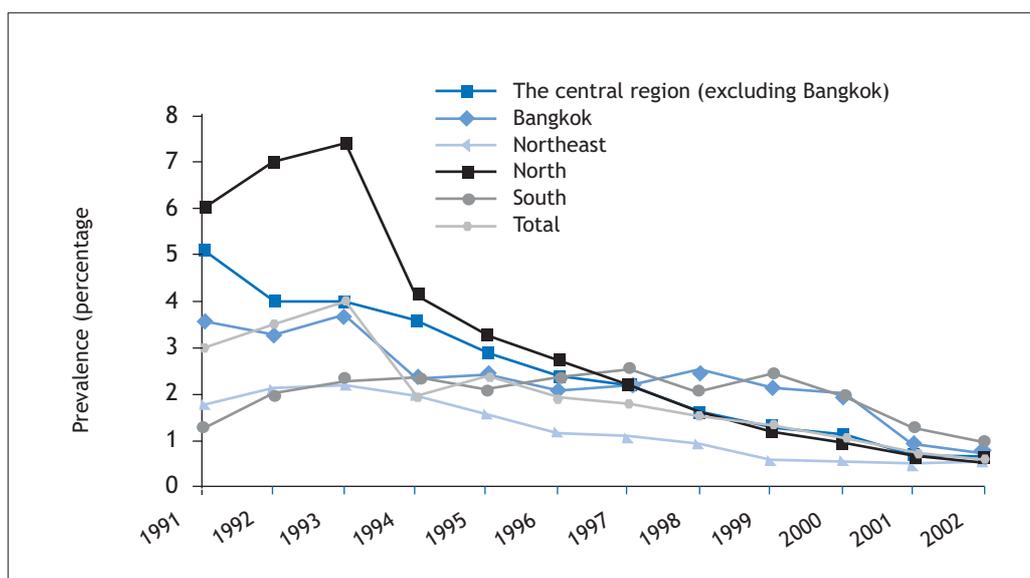
The prevalence of HIV among military recruits in South-East Asia varies by country and region. As access to uniformed personnel is usually restricted, data on the prevalence of HIV among this population is scarce in many countries.

Consider the following examples:

- in Myanmar, approximately 1.6% of new military recruits tested positive for HIV in early 2004
- in Thailand, HIV prevalence among army conscripts decreased from 4% in 1993 to 1.9% in 1998 ²⁴
- 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.²⁵

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.

Figure 8.1. HIV prevalence among Royal Thai Army conscripts, classified by their longest residency during the two years prior to recruitment.

As shown in figure 8.1, the HIV prevalence among Royal Thai Army conscripts has significantly decreased between 1991 and 2002.

Role of Uniformed Personnel in Surveillance

Military recruits

Young males who are conscripted or 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 *female sex workers*. 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. These operations 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 of HIV infection.

Conducting Formative Research

The policies governing the testing of uniformed personnel vary by country. Whereas some countries, such as Thailand, have mandatory HIV testing of military recruits, others, such as India, 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

1. 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.
2. Conduct a situation analysis.
3. Conduct formative research to identify the groups of members of uniformed services at highest risk of HIV infection.
4. Understand the definition of uniformed personnel and what groups might be included in your country.
5. Assess the infrastructure of military and law enforcement authorities for surveillance purposes.
6. Gain collaboration of existing personnel delivering public health interventions, if applicable.
7. Design surveillance approach.
8. Collect HIV sero-prevalence data, behavioural data and STI data.
9. With the collaboration of the uniformed service analyse and disseminate data.

Pre-surveillance assessment

Conducting a pre-surveillance 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 pre-surveillance 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?

Building key 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 (though a less desirable one) is to conduct surveys of persons seeking treatment for STIs at military clinics.

When routine testing is done, 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 it may be logistically difficult for HIV surveillance programmes to reach all uniformed personnel.

Uniformed personnel may or may not be tested for HIV on a regular basis. Table 8.2 summarizes 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	<ul style="list-style-type: none"> Use all the data available. Choose a survey period of a few months. 	<ul style="list-style-type: none"> The advantage of choosing a shorter survey period is that you may be able to ask additional behavioural questions.
No	<ul style="list-style-type: none"> Conduct a survey of a random sample. Try to access persons through medical clinics. 	<ul style="list-style-type: none"> Because lists of personnel likely exist, random sampling methods can be quite straightforward: <ul style="list-style-type: none"> 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: <ul style="list-style-type: none"> survey all individuals seeking care, or just one category of 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.

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 is often used instead of simple random sampling when the sampling list is long or the desired sample size is large, or when access is to a clinic. Random sampling may be difficult due to a lack of computerized personnel lists and due to security concerns.

Cluster sampling - When it is difficult or impossible to make a list/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*. You can then sample in stages by first sampling clusters and then sampling people within the clusters. Cluster sampling is the most common method of sampling in surveys. It has the advantage that the sampling frame is not required to be a list of every person in the target population. Instead, a sampling frame of clusters is required. A cluster is any aggregate of the population of interest (for example, recruitment centres, military units, military bases or camps). Once the clusters are selected, you are required only to list 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 within which the target population is found 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

Both behavioural and biological information on HIV, STI and risk behaviours can be collected in a variety of ways with a focus on sexual transmission and risk. However, it is important to note 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

Biological measure	Notes
Syphilis	Syphilis testing is often the most convenient and efficient biological indicator because the standard tests can be done with the same serological specimen as HIV testing. The test is relatively inexpensive and widely available.
Gonorrhoea	Accurate tests for gonorrhoea are expensive and require a urine specimen.
Chlamydia	Accurate tests for chlamydia are expensive and require a urine specimen.
Herpes simplex virus type 2	HSV-2 testing is a marker for lifetime sexual risk. However, it is less available. To be an indicator for sexual risk, the test needs to 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 standardize a set of “core” or basic indicators of HIV risk among uniformed personnel. These include:

- percent of respondents who received HIV testing in the last 12 months and who know the results (UNGASS)
- percent of respondents who both correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV (UNGASS)
- percent of respondents who have had sex with a non-marital, non-cohabiting partner in the last 12 months (MEASURE), and
 - the number of respondents who report using a condom the last time they had sex with a non-marital, non-cohabiting partner.
- percent of respondents reporting they had sex with a sex worker in the last 12 months (MEASURE), and
 - the number of male respondents reporting condom use the last time they had sex with a sex worker
- percent of respondents who have had anal sex with more than one male partner in the last 12 months (MEASURE), and
 - the percent of men or their partners who used a condom at last anal sex with a male partner
- percent 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 sex workers)
- 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 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.ungass.org/index.php/ungass/ungass/meeting_ungass_targets/ungass_core_indicators.
- The HIV/AIDS Survey Indicators Database of MEASURES DHS includes applicable health indicators that are used to evaluate attitudes and behaviour relative to the health risks measured by HIV and STI prevalence surveys. These indicators are available online at: http://www.measuredhs.com/hivdata/ind_tbl.cfm.

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 research 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/treatment for those HIV infected should be considered where feasible. Doing this provides many benefits over just doing surveillance. 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 should be always given the opportunity to decline any or all participation in the survey or knowing their HIV test results.

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. However, there is no reason not to use 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 minimize them. Explaining these issues to them is part of the informed consent process.

Steps that you can take to minimize threats to confidentiality may include:

- conducting interviews with uniformed personnel in private settings
- keeping names of persons separate from the data collected about them
- limiting access to any identifying information to authorized 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 and/or police force. In settings where HIV infected persons are excluded from service, ensuring confidentiality may not be 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 most susceptible populations 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 sex workers. 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 this information 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.

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 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

HIV Surveillance in Serosia's Armed Forces

Part 1: Collecting information to plan surveillance activities

The current HIV prevalence in the general populations of Serosia is one percent. Serosia 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 Bantak performed unlinked anonymous HIV testing on leftover sero-specimens collected between May and December of last year and published the results. Results of this pilot programme found 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.

The Minister feels that it is crucial to have knowledge about the health status of the military personnel, not only to avoid a sudden incapacity in terms of military readiness due to AIDS, but also to allow the evaluation of the troops' capacity to help each other in cases of blood transfusions necessary in surgery procedures imposed by the theatre of operations and/or 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 gain an understanding of the epidemiological profile of HIV prevalence in the Serosian military population. It is the Minister's hope that results from this survey will facilitate policy making, the creation of recruit entry criteria, medical-services planning, and HIV prevention training activities.

5. What information is required for planning the survey?
6. How will the epidemiology and surveillance team obtain this information?

Part 2: Choosing a sampling approach

Prior to conducting the proposed surveillance activity, the surveillance team must conduct formative research to catalogue the various points of access, locations of uniformed personnel, and health facilities used by military personnel. The surveillance team conducts a pre-surveillance assessment to assess the infrastructure available for surveillance purposes 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 have access to this usually restricted-access population. Prior to beginning surveillance activities, the surveillance team enlists the support of the directors of the various military medical centres.

The surveillance team decides to include 600 male military personnel aged 18 years and above. There are over 50 military installations in Serosia. The country is divided into three military regions:

- Northern Regions: 10 bases
- Central Regions: 25 bases

- Southern Region: 15 bases
- Each military base houses one division of 5,000 men.

The team decides that it is not necessary to include personnel from all installations, but that it is necessary to have the sample reflect the relative military strength of each region.

3. 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 Serosia. As military personnel are not routinely tested for HIV, universal testing using unlinked anonymous testing is not possible. However, a cross-sectional survey can be conducted in a random sample of personnel.

The surveillance team opts 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 selects 60 respondents from each of the 10 selected military bases.

Northern District - 120 participants

- Tapang - Air Base for the Northern District..... (60)
- Idupur - Army Base for the Northern District..... (60)

Central District - 300 participants

- Indam - National Army Training Centre..... (60)
- Indam - National Air Force Training Centre (60)
- Indam - National Special Forces Training Centre..... (60)
- Villipur - Air Base for the Central District..... (60)
- Villipur - Army Base for the Central District..... (60)

Southern District - 180 participants

- Bantak - Bantak Naval Centre..... (60)
- Bantak - Army Base for the Southern District..... (60)
- Bantak - Air Base for the Southern District..... (60)

4. What biological and behavioural information should the epidemiology and surveillance team collect?
5. 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 population to be studied and assess the sample's HIV related risk behaviour and their knowledge, attitudes and practices 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 and HIV rapid testing, and provide referrals to treatment to those who are found to be infected.

With input from behavioural scientists, statisticians, and epidemiologists, MNDS and WHO-SEARO, the surveillance team develop a questionnaire based on Serosia's Demographic Health Survey (DHS). The final version of the questionnaire was pre-tested. Feedback and comments were also 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 persons from whom data would be collected. 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 uniformed personnel. 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 any negative consequences. After the group presentation, each potential participant is briefed again in private and questions are addressed by the counsellor. At this time, the volunteer is given a copy of the consent form to review, fill out and sign. All participants are given a copy of the written consent form to keep for future reference.

Counsellors administer face-to-face interviews in private, using a standard, structured questionnaire conducted with consenting male military personnel. Blood samples are taken by finger-prick for linked, confidential HIV rapid testing, and from dry blood spots (DBS). Results are given to those who choose to receive them and referrals to care are made where indicated.

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 26 years
- The majority of respondents were married (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 Bantak 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 reporting that they had sex with a sex worker in the last 12 months
- Nearly all interactions with sex workers occurred at brothels located near the military bases

- 62% (156/252) of the respondents who reported having sex with a sex worker reported using a condom the last time they had sex with a sex worker
- 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.

6. 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 that 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 married, and many reported extramarital sex with a sex worker 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 a sex worker.

The surveillance team present the following recommendations to the Defence Minister:

1. provide more confidential voluntary counselling and testing at military health centres
2. provide treatment and care for personnel found to be HIV-infected
3. work with brothels near military bases to establish 100% condom programmes.

Notes

Module 6 Summary

- Sometimes referred to as 'at-risk groups' or 'most at-risk populations,' members of high risk groups are at increased risk of passing HIV on to others, or to contracting HIV from others.
- In Asia, populations at increased risk include the following: sex workers (SWs), injection drug users (IDUs), men who have sex with men (MSM), mobile populations, out-of-school youth, prisoners, and uniformed personnel.
- 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. These behaviours include:
 - having sex without using a condom (unprotected sex) with multiple partners and/or having a high number of new partners, and
 - injecting drugs with shared needles.
- Understanding the spread of HIV in high risk groups is essential. Surveillance data can contribute to advocacy for improved care and treatment for most at-risk populations and to evaluate the success of HIV and STI control programmes.
- The first step in planning HIV surveillance in high risk populations is to gain an understanding of the populations. Pre-surveillance 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 high numbers.
- There are several conventional probability sampling methods that can be used for sampling most at-risk populations. 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.
- 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.
- 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.
- The selection of indicators for surveying high risk groups should be determined by the country's data needs. The formative research phase should be used to determine the local questions of greatest relevance to the epidemic in your area.
- Behavioural surveillance indicators should measure behaviours that are key 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, and
 - behaviours that increase the chance that HIV will be transmitted if contact with an HIV infected person occurs.
- 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 injection drug users, have increased risk of other blood-borne infections. Hepatitis C virus is the blood-borne infection most typically measured.
- Many high risk groups are marginalized, and sometimes their behaviour is illegal. It is important to understand your country's laws regarding sex work, injection drug use, and laws requiring reporting of individuals with HIV infection, as these laws may complicate the participation of some at-risk populations.

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ACASI: Acronym for 'audio computer-administered self-interview'.

Accuracy: Refers to how well the sample reflects (nearest to the truth) the study population.

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). Advanced HIV Disease is the term now used for AIDS in updated WHO Guidelines.

AIDS: 'Acquired Immunodeficiency Syndrome.' See Advanced HIV Disease.

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.

Bias: A systematic error in 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.

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 the concentrated to the generalized population.

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.

BSS: Acronym for 'behavioural surveillance survey.'

CAPI: Acronym for 'computer-assisted personal interview.'

CASI: Acronym for 'computerized assisted survey instruments.'

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.

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, etc.)

Cluster sampling: The population of interest is broken into groups or clusters and a sample of clusters is randomly selected.

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 with a common experience or exposure, who are tested repeatedly over a long period of time.

Community-based surveys: Surveys that use samples that have been selected from non-clinical settings. They often include high risk groups, 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.

Concentrated HIV epidemic: The epidemic state in which HIV has spread to a high level in a defined sub-population but is not well established in the general population. (HIV prevalence is consistently >5% in at least one defined sub-population 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.

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.

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.

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.

CSW: Acronym for 'commercial sex worker.'

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.'

Differential recruitment: Recruiters successfully bring recruits in at different rates.

Disinhibition: Poor decision-making when considering risk-taking behaviours.

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.

Enumeration units: The sampling units from the final stage of a multistage sampling design. See 'Listing units.'

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 South-East Asia.

Equilibrium: In RDS, the point in the recruitment process where a variable is not expected to change by more than 2 percent 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.

External validity: The ability to make inferences from the study sample to the population of interest.

Sex workers: 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.

Formative 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 assure that the research team sufficiently understands the community.

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).

Generalized HIV epidemic: The epidemic state in which HIV is firmly established in the general population. (HIV prevalence is consistently >1% in pregnant women.)

Geographical Information System (GIS): System of hardware, software and procedures designed for integrated storing, management, manipulation, analysing, modelling and display of spatially referenced data for solving planning and 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.

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.

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, FSW 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.

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 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 heterosexuals (HRH): Includes and is not limited to: mobile populations, uniformed personnel and sex partners of other/most-at-risk populations MARPs.

HIV: See 'Human Immunodeficiency Virus.'

Homophily: In Respondent-Driven Sampling (RDS), a measure of the tendency of people to connect to other people like themselves.

Human Immunodeficiency Virus (HIV): A retrovirus that causes AIDS by infecting T-cells of the immune system.

IDU: Acronym for 'injection (or intravenous) drug user.'

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.

Indicator: Specific data that are gathered to measure how well a prevention or treatment programme is doing. Defines 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.

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 Respondent-Driven Sampling (RDS), what homophily measures (group similarity based on ethnicity, age, socio-economic status and so forth).

Injection drug users: 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 sampling: Individuals in an institution, such as prison, are sampled.

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 (IDP): 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.

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.

Listing units: The sampling units from the final stage of a multistage sampling design. See enumeration units.

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 Respondent-Driven Sampling (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.

Lessons learned: Information from actual studies that will help you make decisions when planning your study.

Low level 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 or in the general population.)

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.

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.

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.

MICS: See 'Multiple Indicator Cluster Survey.'

Mobile populations: The term used to refer 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 and Evaluation (M&E): Collecting and analysing accurate and reliable information that can be used to improve programme performance and planning.

MSC: See 'multi-stage cluster sampling.'

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.

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.

Needs assessment: A systematic examination of the type, depth and scope of a problem.

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. Full relational network sampling begins with identification of individuals (seeds) who act as entry points to the network.

NGO: Acronym for 'non governmental organisation.'

Non-probability sampling: The sampling units are selected through a non-randomized 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.

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.

Out-of-school youth (OSY): Include children and adolescents 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.

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.

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.

Payment coupon: Kept by the recruiter. He/she will use it to claim an incentive for having recruited a peer into the study.

Period prevalence: Refers to prevalence over a period of time, such as a six-month period.

PLACE: See 'Priorities for local AIDS control efforts.'

PLWHA: Acronym for 'Persons living with HIV/AIDS.'

Point prevalence: Refers to prevalence at a single point in time.

Population: The entire set of individuals to which findings are to be extrapolated.

PPS: See 'Probability proportional to size sampling.'

Precision: Refers to how well the results can be reproduced each time the survey is conducted.

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 a specific group infected. Prevalence is a direct measurement of the burden of disease in a population.

Primary incentive: The incentive a participant gets for enrolling in the study and completing an interview.

Primary sampling units: A sampling frame of a 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 formalizes 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.

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.

Probability sampling: All sampling units in the study population have a known, non-zero probability of being selected in the sample, usually through a randomized process.

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.

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 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.)

Random error: Also called non-systematic error. This is the type of error that results from chance and leads to imprecise results.

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.

RDS: See 'Respondent-driven sampling.'

RDSAT: Respondent-driven sampling analysis tool (a freeware software package for analysing RDS samples.)

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.

Reliability: Refers to how reproducible a result is from repeated applications of a measure to the same subject.

Representativeness: The degree to which the sample truly reflects the study population (that is, whether it is representative of the study population).

Resource assessment: A component of rapid assessment and response (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.

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.

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.

Sample frame: A list of units from which a sample may be selected. A sample frame is a fundamental part of probability sampling.

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.

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 (Sexually transmitted infections), 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 Respondent-Driven Sampling (RDS) recruitment process. From each seed, a recruitment chain is expected to grow.

Sero-prevalence surveys: Surveys that estimate HIV prevalence by testing blood for HIV antibody.

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: Facilities such as STD (Sexually transmitted disease) clinics, antenatal care clinics, blood donation centres, drug treatment programs, prisons and needle exchange programs.

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.

Sexually transmitted infection (STI): Diseases that are spread by the transfer of organisms from person to person during sexual contact.

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.

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.

SRS: See 'Simple random sampling'

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.

Standardized 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 Respondent-Driven Sampling (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.

Stigma: A mark of disgrace or shame. For example, in some societies, being infected with HIV causes a person to be stigmatized.

STI: See 'Sexually transmitted infection.'

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: The selection of separate (independent) samples from each stratum. When the population consists of distinct sub-groups, (for example, age groups or regions) we may need to make precise estimates of our indicators for each sub-group. If this is the case, we use stratified sampling. First we calculate the required sample size for measuring our indicator, then define the sub-group (strata) and randomly sample the calculated sample size in each stratum. Since we want to make precise estimates of our indicator for each stratum, our sample size will be much larger than if we just wanted an estimate for the entire population. We can combine strata estimates to

obtain a population estimate for our indicators. However, this requires that we know the proportion of the population in each strata.

Subcutaneously: Injected below the skin.

Surveillance: The systematic, regular and ongoing collection and use of data for public health action.

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).

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: When we construct the sampling frame, as in simple random sampling (that is, we make a list of everyone in the target population) but rather than selecting names or random numbers, we sample people at regular intervals down the list. For this scheme to work you need to ensure that the list is not ordered in any way that would bias those who are selected in the survey.

Systematic sampling: Every k th unit is sampled from a sampling frame after a random start. Systematic sampling is often used instead of SRS when the sampling list is long or the desired sample size is large.

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: Tuberculosis.

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).

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.

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 conscription: Military conscription in which all physically able men between certain ages (for example 17-28) must perform military service.

Unlinked anonymous testing (UAT): Testing that occurs when a sample of blood that was 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.

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.

Venue: Locations in the community, such as bars or brothels.

Venue-based sampling (brick and mortar sites): 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.

Voluntary migrants: Often referred to as 'economic migrants.' The term 'voluntary migrants' refers to people who temporarily work or travel away from their homes.

Volunteerism: A term to describe overly cooperative subjects, leading to a potential bias if such cooperative people differ from the rest of the population of interest.

The CDC Global AIDS Program (GAP)

The CDC Global AIDS Program (GAP) Surveillance team is 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.

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

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.

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>.

Respondent-Driven Sampling Field Experiences Message Board

A respondent-driven sampling site where people can share questions and receive answers in real time. The Board is not monitored; so it relies on people checking in for now. It requires registration. You will be alerted to new postings if you choose. Feel free to share the web site with other RDS users or others who might be interested.

<http://www.globalhiveevaluation.org/messageboard/topicView.aspx?id=2>.

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. UNAIDS compiles epidemiological fact sheets about each country involved in HIV/AIDS prevention programmes, as well as specific populations.

www.unaids.org.

United Nations General Assembly Special Session on HIV/AIDS (UNGASS)

The 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.ungass.org/index.php/ungass/ungass/meeting_ungass_targets/ungass_core_indicators.

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 South-East Asia, where injecting drug use is known to drive the HIV/AIDS epidemic.

<http://www.unodc.org/unodc/index.html>.

United States Department of Commerce, U.S. Census Bureau's International Programs Center

The International Programs Centre, 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 Programmes Centre provides various country profiles that examine the patterns and trends of the epidemic, as well as maps and tables that serve to summarize the statistics for each region in a streamlined format.

www.census.gov/ipc/www/hivaidn.html.

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.

Unit 1 Answers

Warm-up questions

1. True or false? A high risk group is at increased risk of HIV infection because of higher risk behaviours. *True. Members of high risk groups are at increased risk of contracting HIV and passing the virus on to others due to high risk behaviours, such as, having unprotected sex with multiple partners, having a high number of new partners, and injecting drugs with shared needles.*
2. Which of the following groups are at high risk for HIV infection in the South-East Asia region?
 - a. sex workers
 - b. injection drug users
 - c. men who have sex with men
 - d. all of the above

In the South-East Asia regions, groups at high risk for HIV infection include, but are not limited to: sex workers, injection drug users, men who have sex with men, mobile populations, out-of-school youth, prisoners and uniformed personnel.
3. True or false? In low-level epidemics, surveillance of high risk groups 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.*
6. List the two sampling methods that are commonly used in HIV surveillance of populations at high risk for HIV transmission. *Respondent-driven sampling (RDS) and time-location sampling (TLS) are ideally suited for surveys of high risk groups, especially those that are harder to find.*
4. An example of a potential legal harm to members of high risk groups because of HIV surveillance activities is *arrest (and prosecution)*. *Arrest and prosecution are both potential legal harms that members of high risk groups may experience due to HIV and behavioural surveillance in high risk populations.*

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. List two places where direct SWs (SWs who work exclusively in sex work and have no other occupation) can be found. *Direct sex workers can be based in brothels, streets, hotels and bars, and work exclusively in sex work.*
3. Indirect SWs do not engage in sex work full time, and may have another source of income. They are also called casual SWs or clandestine 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 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 behavioural surveillance approach and questionnaires. *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. For example, male clients of FSWs 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 fixed 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, injection of illegal drugs, etc.*
2. Which of the following sampling methods can be used for surveillance in IDUs?
 - a. *time-location sampling*
 - b. *multi-stage cluster sampling*
 - c. *convenience sampling*
 - d. *simple random sampling from a de-addiction 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, social service organisations, etc.*

4. List two interventions that can help reduce HIV transmission among IDUs. *Officials can help to reduce HIV transmission by promoting sterilisation of injection equipment, providing sterile needles, treating drug addiction, promoting condom use, etc.*
5. What are the ethical issues you must consider when conducting surveillance in IDUs?
Ethical issues to consider when conducting surveillance in IDUs include:
 - *The inability of IDUs to provide truly informed consent when under the influence of drugs or withdrawing from 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 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 both their female and male partners.*
2. List two common 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 who congregate at known locations. Examples of these include dance clubs, gyms, bath houses, parks, etc.
3. Because MSM are often hard to reach because of discrimination and stigmatization, 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?
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 publicized results, physical abuse and imprisonment.

Unit 5 Answers

1. Which of the following terms is used to describe voluntary migrants, and which terms are used to describe involuntary migrants?
 - a. refugees
 - b. displaced persons
 - c. mobile populations
 - d. none of the above*'Mobile populations' is the term used to refer collectively to voluntary and involuntary migrants. The other two terms are types of involuntary migrants.*

2. True or false? Both biological and behavioural surveillance on migrant workers should be conducted regularly every year. *True. This will ensure that in-depth information on this high risk group can be collected regularly.*

3. Of the following, which is *not* a reason why migrants are especially vulnerable to HIV?
 - a. Female migrants often sell 'survival sex' when they have no other source of income.
 - b. Migrants usually only have 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. List two sub-groups that can be considered mobile populations. *Examples of mobile persons are truck drivers, miners, factory workers, fishermen, sailors, etc.*

5. Which type of migration occurs regularly in the South-East Asia region and usually involves young people who move from low-prevalence areas to high-prevalence areas and eventually return home?
 - a. 'circular' or 'oscillating migration'
 - b. gross migration
 - c. step migration

Unit 6 Answers

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 rates. *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 depend 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 and other places where people gather to use drugs, truck stops, 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.*

Unit 7 Answers

1. Which of the following is a reason for high HIV prevalence among prisoners?
 - a. the over-representation of injection 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. sharing 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 prison. *False. HIV infection during incarceration also contributes to HIV prevalence among prisoners.*
5. Cohort studies provide the most exact measurements of incidence. However, 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 are only possible if correctional staffs allow public health workers access to prisoners for HIV testing during their incarceration.

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 affect 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

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; they are likely to feel invincible and take risks, etc.*
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 HIV prevalence studies and other activities involving the non-routine collection of data. *Informed consent is required when conducting HIV 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, the following random sampling methods may be appropriate: systematic sampling, cluster sampling or stratified sampling.*

Appendix E Laboratory Tests Available for Measuring Biological Outcomes Among High risk Groups

	Antibody assays	Performance characteristics	Storage and processing	Notes
Serum				
Assays				
HIV-1/2	EIA, rapid tests.	Excellent.	Transport at +4°C Store at -20°C.	Detect lifetime exposure. Serial testing can be used to determine incidence of infection in a cohort.
Less sensitive EIA for STAHRS (detuned assay)	Less sensitive EIA for STAHRS (detuned assay).	Less sensitive EIA for STAHRS (detuned assay).	Less sensitive EIA for STAHRS (detuned assay).	Less sensitive EIA for STAHRS (detuned assay).
BED capture EIA	EIA.	Excellent.	Transport at +4°C Store at -20°C.	Used to detect recent HIV infection, not dependent on HIV type.
Herpes simplex virus type 2	EIA.	Variable.	Transport at +4°C Store at -20°C	
Hepatitis A	EIA.	Good.	Transport at +4°C Store at -20°C	
Hepatitis B	ALT, EIA, polymerase chain reaction (PCR) RPHA.	Good. Poor, but inexpensive.	Transport at +4°C Store at -20°C.	
Hepatitis C	EIA; recombinant immunoblot assay (RIBA); nucleic acid amplification tests (NAAT), including PCR, SDA and TMA.	Good.	Transport at +4°C Store at -20°C.	

	Antibody assays	Performance characteristics	Storage and processing	Notes
Other tests				
Syphilis serology	Non-treponemal antibody tests (VDRL, RPR) treponemal antibody tests (TPPA, FTA)	Good	Transport at +4°C Store at -20°C	Poorly predictive in early infection
p24 antigen	NAAT	Excellent	Varies by NAAT	Detects replicating HIV. Can be used to detect recent infection in persons who have not yet developed HIV antibody
HIV RNA and DNA testing	NAAT	Varies by HIV subtype		Used like p24 antigen test to detect early infection
CD4 testing	Flow cytometry and others	Choice of method depends on laboratory facilities available	Whole blood required. Transport at room temperature. Analyse within 48 h	Used to stage HIV infection and monitor effect of antiretroviral therapy
Urine Assays				
HIV-1	EIA	High, but more sensitive than serum	Transport at +4°C. Addition of boric acid prevents bacterial overgrowth. Store at +4°C, test within 6 months	Detects lifetime exposure Serial testing can be used to determine incidence of infection in a cohort

	Antibody assays	Performance characteristics	Storage and processing	Notes
Direct detection of organism				
Trichomonas vaginalis	Microscopy and culture	High for culture	First void urine (15 ml), use spun deposit	Leukoesterase dipstick test (LE) may be used to determine who to screen in certain populations
Trichomonas vaginalis	PCR	High	First void urine (15 ml)	Can pool specimens for PCR testing in low prevalence settings to reduce cost
Chlamydia trachomatis	NAAT	High	Varies by NAAT	
Neisseria gonorrhoea	NAAT	High	Varies by NAAT; may require RNA protectant or dilutant	
Neisseria gonorrhoea	Microscopy and culture	Higher in men than in women	First void urine (15 ml) Use spun deposit	
Oral Fluid				
Assays				
HIV 1/2	ELISA, Particle agglutination assays, western blot	High, but more sensitive than serum	Use saliva collection device with preservative. Transport and store at room temperature	Detects lifetime exposure Serial testing can be used to determine incidence of infection

	Antibody assays	Performance characteristics	Storage and processing	Notes
Genital Swabs (Vaginal/Urethral)				
Direct detection of organism				
Trichomonas vaginalis	Microscopy and culture EIA	High for culture, variable for EIA	Wet preparation for microscopy. TV culture medium or TV In Pouch. Transport at room temperature	
Trichomonas vaginalis	PCR	High	Transport at +4°C Store at -80°C	
Chlamydia trachomatis	NAAT	High	Transport at +4°C Store at -80°C	Can pool specimens in low prevalence settings to reduce costs
Chlamydia trachomatis	Direct fluorescent antigen, EIA	Less sensitive than NAAT	Non wooden swabs, sample must include host cells, transport at 2-8°C	
Neisseria gonorrhoea	LCR/PCR	High	Transport at +4°C Store at -80°C	
Neisseria gonorrhoea	Culture	Less sensitive than NAAT	Selective transport media, incubate at 35-37° C in CO ₂ enriched atmosphere	
HSV-2	PCR	High	Transport at +4°C Store at -80°C	
HSV-2	Culture	High-less sensitive than PCR	Transport at +4°C Store at -80C	
HIV RNA		Dependent on specimen collection technique	Cervico-vaginal lavage/swabs in women Semen in men	Quantification requires exact quantity of specimen to be standardized

Source: Adapted from Stephenson JM, Imrie J, Bonell C. *Effective Sexual Health Interventions: Issues in Experimental Evaluation*. New York: Oxford University Press, 2003.

- ¹ HIV/AIDS epidemiological Surveillance & Estimation report for the year 2005, NACO India, 2006,
- ² Nepal Country Report January 2003 - December 2005, Nepalese NCASC, 2005
- ³ Bangladesh National HIV Serological Surveillance, 2004-2005
- ⁴ Bangladesh National HIV Serological Surveillance, 2004-2005
- ⁵ UNGASS National Report: Nepal 2005
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- ⁹ Pisani et al, HIV, syphilis infection, and sexual practices among transgender sex workers, male sex workers, and other men who have sex with men in Jakarta, Indonesia. *Sex Transm Infect* 2004; 80:536-540.
- ¹⁰ MAP (2005). MAP Report 2005: Sex work and HIV/AIDS in Asia.
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- ¹⁵ HIV/STD Prevalence and Risk Factors among Migrant and Non-Migrant Males of Achham District in Far-Western Nepal, 2002, Family Health International
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- ¹⁷ Adolescent and Youth Reproductive Health in Nepal, POLICY, January 2003
- ¹⁸ Sarkar et al, Young Age is a Risk factor for HIV among female sex workers - An experience from India, *Journal of Infection*, November 2005
- ¹⁹ UNAIDS. AIDS in the ASEAN region -facts and figures. December 2006.
- ²⁰ UNAIDS. AIDS in the ASEAN region -facts and figures. December 2006.
- ²¹ Myanmar AIDS Prevention and Control Project, Dept. of Health, *Sentinel surveillance data for 1989-2003*. Yangon, AIDS Prevention and Control Project, 2004
- ²² Indonesia Fact Sheet, WHO 2006
- ²³ HIV infection and risk factors among Bangkok prisoners, Thailand: a prospective cohort study, 2003, Thasiri et al., *BMC Infectious Diseases* 2003, 3:25
- ²⁴ HIV/AIDS prevention and control: an experience of the Royal Army of Thailand, 2004, UNAIDS
- ²⁵ Strong Fighting: Sexual Behavior and HIV/AIDS in the Cambodian Uniformed Services. Ian Ramage, for FHI, 2002.

Module 6 introduces HIV surveillance among high-risk populations. Eight high-risk populations are described in-depth with recommended surveillance techniques. Detailed case studies are provided for each population to help participants think through implementation. After completing this course, participants should:

- be able to discuss the importance of surveillance in high-risk populations
- understand the purpose of pre-surveillance assessments and the role of qualitative and quantitative research in these assessments
- be able to discuss the advantages and disadvantages of various sampling approaches
- be able to discuss how to choose the most effective biological and behavioural measures in surveys of high-risk groups
- understand the special ethical consideration of conducting behavioural and biological surveillance among high-risk groups.

This course is meant primarily for state/national-level surveillance officers. This module can also be used for self-study.

Module 5 is a prerequisite for this module.